University of Alberta

Social Interaction between Adults with Mental Disabilities and Their Community Members

by

Marya Stephanie Owen ©

A thesis submitted to the Faculty of Graduate Studies and Research in partial fulfillment of the requirements for the degree of Doctor of Philosophy

in

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I am myself and what is around me

and if I do not save it, it shall not save me

Jose Ortega y Gasset

Dedicated to the memory of my grandmother

Bella Rose

and her generosity of spirit

Abstract

Program planning for people with mental disabilities has highlighted relationships as a measure of quality of life. Social interaction between people with mental disabilities and their community members has been targeted as a service goal. Previous research on these interactions has identified that people with mental disabilities are at risk for social isolation in institutional and residential settings. As a result, patterns of current interaction between persons with mental disabilities and persons without mental disabilities have been described in the literature, and interventions promoting social relationships have been applied.

The present study explored the social interactions that occurred between three individuals with mental disabilities and their community members. Data were collected through direct observation of the individuals within their community based programs. In addition, an audiotaped open-ended interview was conducted with two of their staff and two of their non-disabled community members.

Three themes emerged from the interview data that reflected the perceptions of social interaction from the viewpoint of the community members and staff interviewed. These were: staff involvement in the process of integration; the need for direct experience with the individual; and the personal qualities of the individual that were not related to their level of disability; which were found to be factors in the quality of the interactions. Observational data supported these themes, although questions arose as to the sufficiency of non-disabled social partners in the lives of the people with mental disabilities. What was clear was a reliance on a systematic approach to inclusion. Within this approach, however, staff required flexibility in order to promote social interactions in individualized ways.

Recommendations for staff training are also presented. They include: a) hiring staff who are confident, outgoing, and familiar with their community, b) teaching social skills within a natural, community-based setting; c) transferring social responsibility to natural support systems only after community members have had continued exposure to the client; and d) promoting reciprocity between the client, agency, and community.

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Chapter I-Introduction

Only recently have assured civil rights for all persons been recognized as applicable to citizens who have mental disabilities. Accordingly, areas within society that may have previously been inaccessible to this population have begun a process of integration, largely under the principles of normalization (Wolfensberger, 1972, 1980). Several empirical studies have provided support for the facilitation of community living, and evidence has accumulated that community residential settings promote adaptive behavior (e.g., Eyman & Arndt, 1982) and language development (e.g., McNutt & Leri, 1979). More recently, a broader approach to planning for individuals with disabilities has been advocated by persons concerned with issues surrounding "quality of life." The concept of "quality of life" has been described by O'Brien (1987) as having the following components: (a) the ability of individuals to have access to other people in their community and to be able to utilize the various services found within their community; (b) the presence of social relationships with friends, family, colleagues, and peers; and (c) the competence necessary in communication skills, self-help skills, and social skills.

The current trend toward the acknowledgment of a least restrictive living environment for people with disabilities supports the construct of quality of life and the practice of deinstitutionalization. Hence, community residential placements are becoming widespread (Switzky, Dudzinski, Van Acker & Gambro, 1988). The rationale for deinstitutionalization is that by allowing individuals with disabilities to live alongside normally-functioning neighbors, the principle of social equity is served. It had been anticipated by advocates of the process that the physical relocation of persons with disabilities would facilitate more frequent social interactions with the non-disabled community. Therefore, with a more normalized living environment, O'Brien's quality of life components such as the presence of social relationships would be realized. Neighboring has been identified as positively related to individual locus of control, self-esteem, happiness, and life satisfaction

(Ahlbrandt, 1984; Unger & Wandersman, 1982). Neighboring involves reciprocal social activity between neighbors that serves a personal, functional, or informational need (Kahn & Antonucci, 1980; Weiss, 1982). In the development of a neighboring relationship, individuals may begin to experience a "sense of community," which involves feelings of belonging and attachment. These feelings of belonging may have important cognitive and affective consequences (Aubry, 1988). Social indicators of a quality life, such as the relationship between neighbors may measure friendship, belonging, personal growth, reciprocity, and choice, and they reflect the substantive need of this population to have their emotional well-being addressed.

The active facilitation of community inclusion by staff for persons with disabilities has been advocated by Klein (1992). The process by which an agency chooses to integrate its clients into a community setting can vary. For instance some agencies do not make any effort to acquaint their neighbors with the group-home residents but rather choose to allow interaction to occur naturally without intervention. On the other hand, many agencies will facilitate community integration through neighborhood educational programs, helping neighbors with household duties such as shoveling the snow, or bringing a covered dish to a neighborhood party during a special time of year. It is important for advocates of deinstitutionalization to evaluate whether or not community placement meets the psycho-social needs of people with mental disabilities with regard to the level and context of their interaction with non-disabled community members. As an initial inquiry into this aspect of deinstitutionalization, the purpose of this research project was to describe the nature of existing social relationships between people with mental disabilities living in community residences and non-disabled community members. An evaluation of social interaction was warranted to ensure the process of deinstitutionalization has not produced, in effect, mini-institutions within the community. This type of evaluation required a descriptive analysis of the quality of actual community member behavior towards adults with developmental disabilities. By proceeding with such an analysis, a more precise indication of how the

community at large responded to integration was realized. For the present study the following two general questions were posed: (a) what type of behavior, do non-disabled community members exhibit in response to the existence of community members with mental disabilities? and (b) what is the context in which this behavior occurs? In short, have advocates of civil rights for persons with mental disabilities accomplished their goal of social equity?

Chapter II-Review of The Literature

Service Trends

During varying historical periods, people with mental disabilities have been regarded as innately immoral, dangerous, and eternal children (Gardner & Chapman, 1993). Accordingly, the quality of service was designed to support the prominent philosophy of the time. Traditional institutions were founded as part of the policies that promoted social reform at the turn of the century, and distinguished between populations of citizens (Lerman, 1982). Residents of almshouses, prisons and institutions for the "insane," feebleminded," and the deaf and the blind were established as benevolent indoor programs. Goddard's introduction of Binet's intelligence test to America, and the subsequent use of it to identify potential criminals, prostitutes and other moral deviants solidified residence in these institutions. Residential segregation ensured that society would be safe from the vagrant misdeeds of the "moron," and through subsequent sterilization, they would be unable to propagate and parent other unfortunate children (Gould, 1981). In the 1920's, the eugenics movement gained support, but by the end of the 1930's there was less of a belief that genetic inferiority was at the root of society's problems, perhaps due to the social experience of the Depression. According to Lerman, the second World War may have sidetracked an ideological shift to release inmates of institutions, but until the people with mental disabilities were considered to have citizenship rights in the late 1960's and early 1970's, they remained. With the concept of normalization, the teaching of adult life-support skills and deinstitutionalization became the standard. Through the process of deinstitutionalization, residents moved from large institutional facilities to smaller community group home settings. These smaller settings allowed for more attention to residents' adaptive skills, and the success of the smaller group residence in improving individuals' self-care, language, and leisure participation is well documented (e.g., Cummins, Polzin, & Theobald, 1990).

Initial models of service in small residential facilities were designed to meet adaptive rehabilitative needs of people with mental disabilities such as cooking, cleaning, and behavior management. These homes were considered by function to be training grounds for these objectives, and to be transitional homes until the individual "graduated" to a more independent living environment (Landesman-Dwyer, 1985). Two problems existed with this model. First, many clients never did reach the point of independence and so were considered and treated as perpetual students within their own homes. Second, the curricula did not typically include less easily measurable goals such as socialization and communication facilitation. In short, it was easier and considered more of a priority to task-analyze steps toward sorting laundry, than it was to task-analyze steps toward finding a friend.

Newton, Horner, Ard, LeBaron, and Sappington (1994) discussed previous measurements of social support. They recognized the lack of direct research of social support and suggested future research methods to measure social relationships. Suggested methods included interviewing a family member or friend of a person who has difficulty communicating to conduct a social support assessment, using longitudinal participant observation to ascertain specific types of social support that might be available to an individual, and using behavior coding to provide information on the nature of social support.

Social Indicators of a Quality of Life

Only recently have caregivers begun to understand the importance of social indicators in defining appropriate service for people with mental disabilities. Furthermore, the residences of the disabled are now more often perceived as homes rather than schools, and so the residents are remaining there for longer periods of time under a "supported living model" rather than a training model. Individual Service Plans that previously only targeted basic living skills are now reflecting clients' social belonging and community integration needs (Schalock & Kiernan, 1990). Goode's quality of life principles as cited

in Schalock and Kiernan (1990) summarized the philosophy that agencies should now be using when planning for individuals with mental disabilities: (a) quality of life means essentially the same thing for persons with and without disabilities; (b) quality of life is basically a social phenomenon and a product primarily of interactions with others; (c) quality of life is the outcome of individuals meeting basic needs and fulfilling basic responsibilities in community settings (family, recreational, school, and work); and (d) quality of life is defined by the consumer rather than by the professional. According to Goode, "quality of life issues should be defined by consumers and other citizens rather than professionals in the field. Ultimately it is how the individual perceives and evaluates his own situation, rather than how others see him, that determines the quality of life he or she experiences" (p. 158).

Denoting the aspects of a quality of life and evaluating those aspects have been a research priority. Hughes, Hwang, Kim, Eisenman, and Killian (1995) recently reviewed "quality of life" measures in the literature. The authors wanted to compile a consensus of the components of a quality of life, assess the support of these components, and establish a knowledge base. In their review, they identified 15 components of a quality of life that were measured. In 87 reviewed studies, social relationships and interaction were measured most frequently. This included interpersonal interactions that reflected a relationship with a girlfriend or boyfriend or neighbor. Unfortunately the study only discussed how often "quality of life" was utilized as a dependent measure, and not the value of such a construct in determining the satisfaction of people with mental disabilities. The authors concluded that there appeared to be consensus within the literature on the aspects of quality of life, and social relationships and interactions were a significant dimension of quality of life.

Parents of students with moderate and severe/profound mental disabilities have been asked about their preference for content of instruction for their sons and daughters (Hamre-Nietupski, 1993). Parents of students of varying ages with moderate disabilities preferred on average that 42% of their children's week involve functional life skill training,

36% involve academics training, and 22% involve friendship development. On the other hand, parents of children with severe or profound disabilities preferred that 50% of their children's week be devoted to functional life skill training, 14 % to academics, 26% to friendship development, and 11% to other curriculum such as speech therapy and art. Unfortunately, data were not presented that reflected possible differences in parental preference based on the age or grade level of their sons and daughters. It would be interesting to note at which point in the child's development do parental expectations for educational instruction change from skill or academic development to social development or vice versa.

A longitudinal study was undertaken of 85 adults with mental disabilities who were moved into independent housing and competitive employment from a "rural community based program" (Schalock & Genung, 1993). Subjects were grouped into either those receiving or not receiving formal support services. Those not receiving formal services tended to be higher functioning than those receiving formal services. Subjects were evaluated on several outcomes including current status, quality of life, and movement patterns. Subjects were asked to think about and describe their social networks to the researchers and then data were coded by relationship to the person, frequency of contact with the person, and type of activities engaged in with the person. Subjects were also asked to think about and describe their activity schedules and their satisfaction levels with their life. The authors found that people not receiving formal services obtained more support from family, advocates, and neighbors than did people receiving formal services, who obtained most of their support from co-workers, roommates, and staff. Although the non-serviced group appeared to take better advantage of community services, the serviced group and non-serviced group did not differ in their level of community integration. The authors suggested further study into natural support paradigms in community integration, and the development of networking and reciprocity skills among individuals with disabilities.

Social Skill Development

Chadsey-Rusch (1992) provided a definition of "social skills" in order to aid in measuring them in vocational settings. Using several definitions, she developed the following components:

1. Social skills are learned and rule governed. There are acceptable and unacceptable social skills, and success might be evaluated by the type of response that the social interaction elicits.

2. Social skills are judged competent or incompetent by others. Competent skills are likely to be received positively by others, whereas incompetent skills are likely to be received negatively by others.

3. Social skills are functional in that they are used to meet individual needs and goals.

4. Social skills are variable according to the context .

5. Social skills involve both observable and non-observable cognitive and emotional aspects.

The very definition of mental retardation is now being criticized for its lack of attention to the social aspects of adaptive behavior. Currently the definition of mental retardation provided by the American Association on Mental Retardation (AAMR) includes: significantly subaverage intellectual functioning, limitations in adaptive skills, and onset prior to age 18 years (American Psychiatric Association, 1994). Greenspan and Granfield (1992) have argued that the present definitions of adaptive behavior and the instruments used to measure it, are more closely akin to psychopathology than to adaptive skill. Maladaptive behavior can occur in the dually diagnosed, however to assume that a person with retardation by definition is psychopathological is erroneous. Rather the authors asserted that social competence be recognized within the definition of mental retardation. By replacing the term "maladaptive behavior" with adaptive skills that include "social intelligence" (social cognition and social behavior) a more representative construct of

mental retardation can be achieved. Though the term "maladaptive" might invoke images of odd or deviant behavior, I would suggest instruments such as the Vineland Adaptive Behavior Scales (Sparrow, Balla, & Cicchetti, 1984) that are used to assess adaptive skill *do* focus mainly on activities of daily living and communication and only briefly on aberrant behavior. Perhaps it is the inclusion of "mental retardation" in the DSM-IV at all which concerns Greenspan and Granfield. The DSM-IV is a categorical device that distinguishes between psychopathologies, hence its inclusion might imply that people with mental disabilities are somehow ill and need to be cured.

Training in social skill competence has been demonstrated within an institutional setting. For example, Foxx and Faw (1992), examined the maintenance of social skill training of nine adults with mild to moderate mental disabilities after eight years. The initial training was conducted using a board-game and playing cards to depict social situations. The follow-up component involved role playing and use of scripts to assess maintenance. The subjects were reassessed according to the correctness of social responses and mean number of words per response. Apparently, five of the nine subjects maintained correct responding levels and four of the nine subjects displayed more words per response after the eight years. The authors cautioned that there was no investigation as to why this training had maintained and what other variables might have played a part. Although they recommended more research in this area, it may be stated that to continue social skill training within institutional care without an understanding of its benefit to the client would be an exercise in futility. This is especially true if analogous conditions continue to be used without an investigation into the generalizability and efficacy of such training for the subject.

In an interesting study from Stewart, Van Houten, and Van Houten (1992), peer therapists were used to increase social interaction between residents with mental disabilities and dually diagnosed residents of a mental health center. Socially withdrawn peers with mental disabilities were encouraged to interact socially with other withdrawn residents

through a reward system. The results indicated that dually diagnosed and withdrawn individuals can effectively act as social therapists when paired with other dually diagnosed and socially withdrawn individuals. In order for the social interaction to generalize beyond the first peer therapist to other residents, however, subsequent peers had to be introduced. Social interactions continued even though token reinforcement was discontinued, and the authors speculated that the social interactions themselves became reinforcing, thus maintaining the behavior through natural consequences.

More recently, Newton and Horner (1993) taught staff of residential programs strategies to facilitate social relationships for people with severe disabilities. Their dependent measure "social integration" was defined as the number of activities a resident had with members of their social network within a certain time period. Using strategies such as helping residents find preferable activities and matching their interests with those of community members the staff significantly increased the residents' social network size and participation in social activities with community members. Again, the data from this study were not coded according to who within the community were accessed by the participants. The authors did state as an example: "if a participant liked fishing, staff members would try to identity one or more friends, neighbors, or other community members who also liked to fish" (p. 39), but they did not report the context of the relationship any further.

Owen, McDonald, and Baine (1994) used direct observation to characterize patterns of communication between staff and residents in a group home setting. Intent of the speaker, proportion of discourse, and group turntaking were coded and analyzed by means of a video recorder and a modified data collection sheet. Two staff members and four residents, varied in their amount of verbal expression, however, staff members accounted for the majority of utterances and topic initiations. An analysis of turntaking patterns suggested that in group discourse, questioning type speech preceded a greater number of subsequent conversational turns than did command-type or declarative-type speech.

Social Interaction Between Persons With and Without Disabilities

Research indicates that simple physical relocation of people with disabilities might not result in significant development of social relationships (Lowe & De Paiva, 1991). Intervention studies have typically targeted the skills of the group home resident rather than the behaviors of the non-disabled neighbor in order to expedite social interaction. Although significant gains in residents' adaptive living skills have been indicated, it has been found that people with mental disabilities tend to be lonely and isolated, have very limited social relationships, and live on the fringe of community life (e.g., Malin, 1982).

There have been attempts to compare the social systems of adults with and without mental disabilities. For example, Rosen and Burchard (1990) interviewed 27 adults with mental disabilities and 27 adults without mental disabilities using a social network questionnaire. Participants with mental disabilities lived in community based supervised living situations while the comparison group were matched according to marital status, sex, age, and community size. The interview yielded data on: (a) the size of the support network; (b) the relationships within the support network; (c) the perception of level of support given by the network; (d) the satisfaction with contact; and (e) the extent of reciprocity. Participants were also asked about location, purpose, and frequency of community activities and with whom they participated during these activities. The researchers found that the frequency and types of community activities were similar for both participants with and without disabilities, but that adults without mental disabilities reported almost twice the number of network members than did adults with mental disabilities. Adults without mental disabilities also reported seven times as many reciprocal relationships where each partner initiated supportive contact. Adults without disabilities reported having significantly more friends within their social network whereas adults with disabilities reported more staff and other service providers. Both groups perceived the same levels of satisfaction and support of their network members.

Kennedy, Horner, and Newton (1989) were also interested in tracking the social contacts of individuals with severe disabilities and their community neighbors. They trained staff in small community-based residences to record the type and frequency of contact for 23 adults over a 2 1/2 year time period. Over the period of data collection, the 23 residents engaged in social interactions with an average of 63.5 people outside of their roommates and staff. The majority of these contacts were with friends and acquaintances, yet these relationships were described as transient. Although family constituted a small proportion of social contact, they were the most stable and enduring relationship in the residents' lives. The data were not broken down to describe the role of the social contact beyond friend or acquaintance so it is not clear from this study whether neighbors played a significant role in the social life of the residents or whether the acquaintances or friends were mostly comprised of other community members such as store clerks or recreational partners.

Kuder and Bryen (1991) analyzed the communicative performance of institutionalized persons with mental disabilities. Ten residents were observed within the institution's academic classrooms and residential living areas. Observations were conducted around lunchtime and after school in the residential living areas. Each subject was observed twenty times in total over an evenly distributed period and a total of 3, 476 verbal interactions were observed. They found that 67% of interactions occurred in the classroom setting compared to 33% in the residential setting. In the residential setting, more than two-thirds of the verbal interactions were initiated by the subjects. Staff initiated 26% of the conversations, while peers rarely initiated interaction with the subjects. The researchers coded the language according to whether the participants used a conversational "encourager" or "discourager," and whether the topic was "social," "control," "instructional," and "idiosyncratic." It was found that nearly half the residents' verbal initiations to staff members were on social topics but staff members used more control types of initiations towards residents. Residents tended to respond more to encourager

types of initiations than to discourager types of initiations, except when staff used social topics. According to the authors, the study was somewhat limited because it only included verbal residents. They suggested that further research in this area should be carried out in community-based settings and include nonverbal as well as verbal participants.

Methods of the assessment of integration have been described by Storey (1993). The author distinguished between molar and molecular evaluation processes that have been utilized in this field of study. Four indices of integration: physical, social, relationships, and networks have been evaluated within the literature with varying degrees of success in understanding better how and why interactions between people with and without disabilities take place. Storey recommended that cases of successful integration be described in hopes of identifying useful dependent variables. He also suggested that it will be necessary to know the conditions under which integration is achieved

Noting the lack of research concerning friendships of adults with disabilities, Barber and Hupp (1993), used questionnaires and demographic data to compare patterns of friendships between individuals with and without mental disabilities. They found that the non-disabled comparison group and individuals with disabilities living in smaller homes reported similar numbers of close friends and far more close relationships than residents of large facilities. As well, the comparison group reported significantly more distant relationships than either the small home or large residential groups with disabilities. The domains where the friendships were formed were also of interest. Most of the non-disabled group met friends through work and in the community whereas residents of both large and small residences primarily met friends within the home, then through family, work, recreation, and finally, the community.

A similar study (Lakin, Bruininks, Chen, Hill, & Anderson, 1993) surveyed the staff of 336 persons with mental disabilities from 181 family foster homes and group homes in order to answer a number of questions pertaining to integration of people with mental disabilities within the neighborhood and larger community. Their sample included people

with borderline, mild, moderate, severe and profound degrees of mental retardation. It was found that there were non-significant differences between residents of either group homes or foster care homes in terms of the number of friends they reported. Interestingly, staff reported that among residents who could talk, 19% were satisfied with no friends while among residents who could not talk, 50% were satisfied with no friends. How exactly the staff members were able to ascertain this from a non-verbal resident was not clear! They also found that slightly less than half of residents were members of a group that met consistently and most residents defined their "best friend" as either being another resident, a day program peer or a staff person. Contact between friends was mostly initiated by the friends as opposed to a formal program directed by the residence. People who lived in small foster homes were more likely to have met and to have been invited into their neighbors' homes than residents of group homes, and perceived a greater level of acceptance by their neighbors than residents of group homes. Group home residents participated in more leisure activities than foster home residents who more often attended church. Less than half of all the residents reportedly had regular contact with non-disabled members of the community other than staff or family. The authors' concluded that social activities within the community seemed to involve more passive than active participation by the residents with disabilities. They recommended that further research in this area should focus on longitudinal studies "reflecting the dynamics of growing community competence including the effects of time, training and other experiences"(p. 627) on people with mental disabilities.

Other studies have also only implied the role of the community in the social life of persons with disabilities. For example, Krauss, Seltzer, and Goodman (1992) described the social support networks of adults with mental disabilities who live with their parents. They found that for a great proportion of these adults, family constituted the majority of social relationships. About half of the sample reported having "no friends" and the rest of the social network was comprised of shared friends between the mother and the son or

daughter with the disability. Social isolation was most common for males and for individuals with severe mental disabilities. Although the authors reported that most of the members of the network were within an hour's driving range of the participants, they did not expand the nature or contexts of the friendships.

A recent study by Newton, Olson, and Horner (1995) used both interview and survey methods to identify factors that contributed to stable social relationships between adults with mental retardation and community members. They found that success and stability in these relationships seem to depend on: (a) the fact that many friendships began as staff-client relationships; (b) the community member's willingness to initiate and coordinate the activities; (c) the reciprocity of the relationship; and (d) mutual pleasure and need of the relationship; and the individual characteristics of the person with mental retardation.

Interaction among workers with and without disabilities appears to have been studied more frequently than social interaction between community members with and without disabilities. Ferguson, McDonnell, and Drew (1993) directly observed six employees with moderate or severe mental disabilities and their co-workers in restaurant settings. They found that workers without mental disabilities initiated interactions with coworkers far more often than did workers with mental disabilities. Workers without mental disabilities gave more direction to co-workers, asked more questions of co-workers, and initiated teasing and joking more frequently. Shafer, Rice, Metzler, and Haring (1989) used a survey method to question 212 co-workers of employees with mental disabilities. The authors found that co-workers were more accepting and comfortable with people with mental disabilities than were non co-workers. They also found that most of the work place interaction between workers with and without disabilities was centered around task performance rather than social interaction. An interesting finding from this study was that individuals with severe and profound disabilities were perceived more favorably by their non-disabled coworkers than were individuals with mild or moderate disabilities.

Storey, Rhodes, Sandow, Loewinger, and Petherbridge (1991), assessed social interaction patterns of employees in a supported employment setting. The assessment took place over a one year period and involved eight employees with, and seven employees without disabilities. Observation sessions lasted 15 minutes, which yielded a total of 60 recorded intervals per session. Sessions were limited to actual work hours. Observers used a momentary time sampling procedure to rate the various categories of social interaction. These categories included requesting assistance, providing instruction, providing compliments, and engaging in personal conversation. The researchers found that employees with disabilities tended to interact more with the employment specialists. These interactions involved receiving of instruction and compliments more frequently than did the interactions involving employees without disabilities. The employees without disabilities tended to engage more in work and personal conversation with co-workers, and they generally had interactions with a greater number of different people than the employees with disabilities. The researchers also found however, that the interaction patterns varied widely for each of the individual employees.

Assessment of social integration within a supported community based work environment was also carried out using a direct observation approach by Parent, Kregel, Metzler, and Twardzik (1992). Fifteen pairs of workers with and without disabilities were observed using a time sampling and frequency recording procedure. Interactions were coded according to type of interaction (initiation, response), content of interaction (work related, nonwork related) and propriety of the interaction (appropriate, inappropriate, unknown). It was found that frequency of interaction was similar for supported and non-disabled workers, however, coworkers engaged in more work related interactions than supported employees. Co-workers also participated in more breaktime interactions and were more appropriate in their interactions than the supported employees. It appears that individuals with disabilities may need support in establishing and maintaining social contact

during times (e.g., coffee breaks) in which there is less structure and pressure to communicate by non-disabled interactional partners.

An interesting investigation by Butterworth and Strauch (1994) looked at predictors of success in the workplace for adults with mental disabilities. Supervisors and co-workers of 98 individuals with mental disabilities rated their job performance and social interaction skills. The authors found that supervisors and co-workers' perceptions of social skill competence of the subjects predicted their perception of the subject's competence as workers. However, the research also found that perceptions of social competence could not predict the formation and maintenance of non-work related social relationships. Therefore, other factors than the competence of the subjects with disabilities, might have accounted for their ability to integrate socially in the work place. The authors suggested further study of co-workers' and supervisors' knowledge and experience with people with disabilities, and the culture of the work environment, to help identify those factors which lead to successful social integration.

Summary and Conclusions

Current studies have found that there is an active process of integration that has been used by agencies and professionals. Furthermore, a description of social interaction between adults with and without disabilities in controlled settings has been presented in the literature. We have learned about the general patterns of social interaction between people with mental disabilities and others in segregated and non-segregated settings. The literature does not, however, adequately describe the in-depth behavioral patterns of interaction between residents with disabilities and their community members without disabilities. As community integration increases, information about these interactions in uncontrolled natural environments is necessary to have. It is acknowledged that social interaction is a component of a quality life and should be facilitated within the workplace and within the broader community. However, there are few studies that have attempted to track social interactions and those which have appear to be narrow in scope. More attention has been

paid to interaction with co-workers perhaps because of a growing interest in vocational integration and supported employment. Contact between community members with and without disabilities on the other hand seems to be given only cursory mention within a broader evaluation of community interaction. It is unwise to simply assume that social interaction is taking place between community members, or to disregard the importance of a community relationship. This is especially true for people with mental disabilities, who have historically lived on the fringe of community life and who may be limited in their abilities to develop and maintain social relationships. Men and women with disabilities in residential homes are typically dependent on staff to facilitate the practical prerequisites to community integration (Ashman & Suttie, 1996). There is therefore a need to examine the day-to-day practice of staff and client in their journey toward connection in the community. This study explored such connections in order to gain access into the nature of integration in our society.

The following chapter provides the method for the present study.

Chapter III-Method

Research Questions

The following research questions address the consequences of deinstitutionalization and the implications of social integration in our communities.

1. What is the day to day pattern of social interaction between three adults with varying levels of disability and adults without disabilities in the community?

2. What are the experiences and perceptions of non-disabled adults regarding social interaction between adults with disabilities and the community?

Rationale for the Present Study

This study was necessary to discover what occurs in communities where adults with mental disabilities live. It would be erroneous to relocate people from institutions to communities and assume that the purposes of deinstitutionalization would automatically be fulfilled. It was hoped that the consequences of deinstitutionalization would be a normal life where people with disabilities would live much the same way as others. However, segregation need not only be physical. If people with disabilities in the community do not enjoy social contact with their community members, philosophy and practice fail to meet, thus rendering the construct of normalization to the annals of debate.

The availability of a community member to provide social support to a person with a disability cannot be overlooked as a service goal. There are a number of studies that look at the quantity of community-based relationships for individuals with mental disabilities. Few, however, seek to describe the experience of those engaged in a community-based program that is designed to develop these relationships. The qualitative approach in the present study allowed an investigation of how the participants with mental disabilities encountered the people in their community, and how those people responded to them. The information that was derived from these encounters provided a greater awareness of how

these programs are reaching their goals of inclusion, and how these goals might or might not be benefiting their clients.

Rationale for a Qualitative Approach

To answer at least in part the question of how adults with mental disabilities are integrating into the community, a qualitative methodology was chosen because of its emphasis on depth of experience. In the field of education, the integration of people with mental disabilities is a relatively new phenomenon, and has only become a trend in the last 30 odd years. Even more recent is the practice of closing sheltered workshops and day programs in communities and adopting a living skill curriculum that acknowledges the need for real world experiences, hands on education, and training in vivo. Because this is such a new area of education, little research has been attempted out of the controlled environments of the activity and vocational centers. This being the case, I felt that a descriptive understanding of the current integration practices and outcomes for a small number of people with mental disabilities fulfilled the criteria for an "exploratory" type of study. An exploratory study was chosen in order to investigate the little understood events of integration, to identify and discover important variables related to these events, and to generate hypotheses for further research. Social interaction between the disabled and non-disabled was investigated using two methods: direct observation and interviews. All data were collected within uncontrolled naturally occurring environments to allow for the most ecologically valid understanding of social interaction. Observations were conducted prior to interviews in order to a) view the interactions without knowing the perceptions and interpretations of the participants, and b) understand the context of the interactions and apply that context to the subsequent interview questions. The interview questions did not necessarily reflect actual events that had been observed, but understanding the environments in which the interactions took place, and the nature of those interactions, provided a shared frame of reference for myself and the interviewees.

Credibility

Qualitative research begins with different assumptions about events being described than quantitative research. The qualitative design is not experimental and there are not the typical concerns of history, maturation, or statistical regression. There are other factors which must be considered in qualitative inquiry in order to enhance its credibility. The credibility of my findings are enhanced in three ways. Firstly, I have a strong personal and professional understanding and interest in the subject. This understanding of the history and context of these participants aided in the interpretations of the events and interviews. By stating my presuppositions, the reader is better able to judge the effect my biases may have had on the subsequent interpretations. Secondly, I am able to provide an "audit trail" of the steps I went through during the collection and analysis of the research. A portion of the audit trail (Appendices D, E, F, G) can be found in this document to allow the reader to follow the process of interpretation for the four interviews. Thirdly, the data in this study was triangulated in two ways: triangulation of method and triangulation of data. Triangulation of method refers to the use of two separate methods (observations and interviews) to address the same phenomenon. Triangulation of data refers to the use of different data sources (participants and settings) for the same phenomenon.

There may be difficulties in utilizing a qualitative method to describe an event from the perspective of scientific research. The rigor of qualitative research has been questioned in terms of its adherence to the rules of reliability, validity, and objectivity. This concern for rigor has been reviewed by Sandelowski (1986). She outlined the many difficulties of even ascribing a single criticism to the use of qualitative research because the definition of qualitative research is in itself diverse. For example according to Sandelowski, methods of qualitative research include grounded theory, phenomenology, feminist methods, and historical and philosophical inquiry where each method has its own set of rules. The question arises that if quantitative and qualitative research methods hold polar positions, then the problem of applying quantitative research standards to qualitative methods

becomes irrelevant, indeed a matter of comparing apples and oranges. According to Sandelowski, quantitative research may be viewed as a science, where language and procedure are standardized to ensure reliability and validity. Qualitative research on the other hand may be viewed as an "art", where

> every human experience is viewed as unique, and truth is viewed as relative. The artistic integrity, rather than the scientific objectivity, of the research is achieved when the researcher communicates the richness and diversity of human experience in an engaging and even poetic manner. (p. 29)

The metaphor of art is an interesting one. Much like a visual artist must interpret his or her subject using the medium of paint and canvas, so must the qualitative researcher interpret a part of the world using the medium of observation or interview. The researcher and artist are both neccessary vehicles in order for the subject to reach and move an audience.

According to Guba and Lincoln (1981) credibility resides in the description of the experience and the ability of the reader to recognize that description as being their own. As well, a study may also be considered credible if others may recognize the experience from the study upon seeing it for the first time. Credibility may also be enhanced by the researchers' acknowledgment of their own behavior and experience with regard to their subjects and their method. It is this acknowledgment and understanding that allow the researcher to distinguish between their subjects' experiences and their own influence on the descriptions of the experiences. The problem of representation in qualitative research is one of depth rather than breadth. The goal of the qualitative researcher is to choose the most representative sample possible, with the greatest amount of experience with the events under investigation. It has been argued that collecting behavioral data in the natural environment (free of controlling conditions) actually supports the generalizability of the findings. If this is possible then the credibility of the research is enhanced.

In a more recent article (1993), Sandelowski again addressed the question of reliability and trustworthiness in qualitative research, and discussed the procedure of

"member checking" as a way to enhance the rigor of qualitative work. Member checking requires the research participants to verify their own narrative interviews and allows them to corroborate and/or correct a researcher's interpretation of their stories. This however, may result in a number of difficulties for the researcher. For example, if the participants disagree with an interpretation of their story by the researcher, they may erroneously prevail upon the researcher to alter his or her own interpretations. Sandelowski disputed the entire notion of reliability in qualitative research. The process of "member checking" of ideas and synthesis must be recognized as being "revisionist" since reality changes as perceptions do and the "correct" interpretation may not lay with either the researcher or the subject because of the subjective nature of data collected through memory and recall.

Researcher's Presuppositions

I have been long immersed in the area of mental retardation and integration. My work with the mentally disabled population and my education in this field have integrated with my natural sense of justice to produce a deeply held belief in the right of people with mental disabilities to live well in the community. I have organized my belief system into three themes that elucidate my preconceptions further: the civil rights of people with mental disabilities, the ability of all people to learn and develop, and the benefit of community living.

1. The Civil Rights of People with Mental Disabilities

All people, no matter their level of intelligence, have the right as citizens to live in an environment that promotes and facilitates their health and well-being. This includes people with mental disabilities no matter the level of support needed. To deny this under the guise of paternalism is untenable.

2. The Ability of All People to Grow and Develop

In my experience, all individuals, no matter their level of retardation can learn in many different domains. The rate and increment of development will depend on their skills

and abilities, the quality of the teaching plan, the consistency of training, and the propriety of the goals.

3. The Benefit of Community Living

Living within a community setting, as opposed to an institutional setting appears to facilitate social, adaptive and communicative skills. This is likely due to a change in rehabilitative philosophy from custodial care to active teaching. Social modeling, natural reinforcement and increased stimulation may also account for the remarkable changes I have witnessed in people who have moved from an institution into a home.

In acknowledging my own thoughts, perceptions, opinions, knowledge, and biases, the reader is better able to judge the credibility of the study I have undertaken. As well, in formulating my own presuppositions, I am able to ascertain to a better extent what aspects of the research may be considered participant driven and what might be considered researcher guided.

Selection of Participants

A qualification for interview participants is that on a day to day basis they have experienced the phenomenon in question, and a sample with the widest range of variation in the phenomenon, settings, or people under study is considered beneficial. Preferred subjects would be centrally involved with the phenomenon and possess a willingness and capability to verbalize descriptions of their experiences. In this study I used a purposeful sampling strategy (Patton, 1990) in order to gain the greatest understanding of the events under study. In order to understand the practice and nature of social integration, it was necessary to include people with mental disabilities and people without disabilities involved in the integration process. In the case of people with mental disabilities, it may be difficult if not impossible for many of them to verbalize their experiences and conceptualize their world. This is especially true of people who are more severely impaired. It might be argued then, that either qualitative or more specifically, interview research may be precluded for this population. Perhaps this may be why survey studies of the people

without disabilities dominate this field. I believe though, that those with a mental disability should not be excluded from this type of research because it is their very experience that requires investigation. Therefore, an interview with the non-disabled participants was utilized in this study, as was direct observation with participants with disabilities who could not be interviewed directly.

Inclusion Criteria

A number of criteria were established to determine an individual's eligibility for the study. Two groups were targeted. The first were participants who had a primary diagnosis of mental retardation. These participants were currently served by an agency, over 18 years old, and graduated from the regular school system. Sampling was purposeful in that the participants and their guardians were chosen by the primary researcher because of their eligibility and through a prior professional contact. All three were ambulatory, and had one-on-one support workers. In order to sample a range of experiences, three individuals with varying degrees and type of disability were chosen. All were clients of a non-profit agency and were participating in a "community options program." Initially, to request assistance in choosing participants for the study, two non-profit agencies were contacted. First, the program administrators of each agency concerned were contacted and informed of the nature of the study. They were also given the proposal to read. Once the agency's administration agreed to participate in the study a letter of invitation was sent to potential participants and their guardians or families. Potentially interested guardians were then given further information in a face-to-face meeting. After securing voluntary written consent and assent from the clients and their guardians, the field was narrowed to three participants with disabilities. Two were clients of the "Parkview" agency and one was a client of the "Riverview" agency.

The second group of participants included four non-disabled individuals who were able to comment on the process of social integration from a personal perspective. They all had a relationship with one of the participants of the first group and included two staff

members, an employer, and a friend. All of these participants were contacted separately and invited to participate in the study. They were informed that I would be accompanying them while observing their client or friend and would also be interviewing them for the purpose of gaining their perspective on the social integration of the participant with the disability. All were then given an informed consent form to read and sign (see Appendix A). Figure 1 provides a brief description of the participants in this study, and their relationships to each other. A more detailed description of the participants will be provided later in the manuscript. The actual names have been changed in order to protect the confidentiality of the participants. Names that begin with "D" are used for participants with disabilities, and names that begin with "S" are used for participants without disabilities.

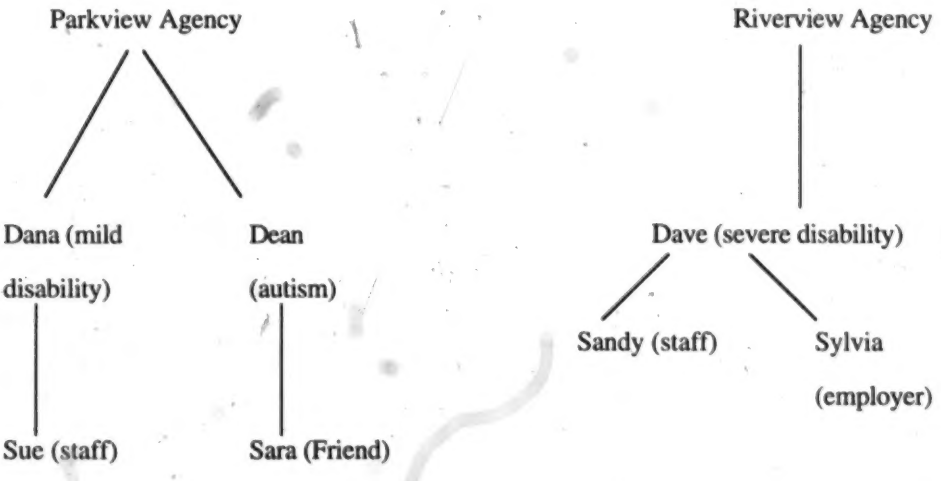

Figure 1. Description Of Participants

Data Collection

Observations

There were two separate methods of data collection used to answer the research questions. First, I observed the participants in their natural environments. Observations of the clients took place when they were out of their homes and participating in community activities and community life. Data were not collected while the participants were in their workers' vehicles, at their agency buildings, or within their own residences, because interactions between the clients and their staff teams were not included as a unit of analysis.

The first participant, Dana, was observed using a continuous observation procedure where every interaction was documented during the observation periods. Descriptions and frequency counts of this participant's interactions within her community were collected in order to gain a broad perspective of the nature of the interactions that she experienced. This was feasible with Dana because of her level of communicative skill, her ability to initiate and maintain interactions independently of her staff member, and her wide use of services within her community. I initially spent about one hour with Dana interviewing her and answering any questions she had, in order to reinforce the purpose and details of our prospective time together and to build rapport. Dana showed me around her apartment and we discussed her home, her cat, and her family. Following the interview, Dana was again contacted and asked if she would like to participate in the second stage of the study which involved the observation and data collection in the community. Again she agreed. During the observation period, I attempted to maintain a discreet distance from Dana and her worker when appropriate (such as in a grocery store). If, however, Dana or her worker directed a comment or question toward me, I responded in context. Initial observations of Dana were made using a data collection sheet that had been adapted from O'Neill, Horner, Albin, Storey, and Sprague (1990) (see Appendix B). The sheet was reduced in size and hidden in a day timer in order to appear as inconspicuous as possible. In order to establish

the role of the community contacts, Dana was asked to identify the people she communicated with following the interactions. Soon Dana would offer the role of each person she knew independently following each interaction.

Dana was initially observed over a 4 day period totaling 6 hours. Time spent with Dana in the community occurred during the daytime hours somewhere between the times of 10:00 and 3:00 each day. Typically, these were the hours that Dana spent in the community. Her evening activities involved segregated functions within the agency, and her early morning and late afternoon routine tended to be home based. I accompanied Dana alone and with the worker. During times that I was alone with Dana I did not hang back to observe, but accompanied Dana as a companion.

Following Dana I observed Dave and then Dean. Frequency counts of interactions for Dave and Dean were impossible as their communicative abilities were limited to such a degree that an isolated interaction involving only them and a community member without facilitation from staff tended to be minimal. As well, their community-based programs did not consistently include functional living tasks such as shopping or banking and the goals of their programs were more focused on community contact and awareness rather than independent living skills. Therefore observations are presented for them in narrative form only. The second participant, Dave, was observed over a 5 day period (approximately 15 hours). When observing I endeavored to accompany him and his staff member in the community as inconspicuously as possible, taking notes as we went along. Because Dave has his staff by his side almost constantly, I walked beside Dave and his staff, so as not to draw attention to myself and hence to Dave. During times in which we were in a busy milieu (such as in a grocery store), I attempted to separate myself for a couple of feet and observe surreptitiously. After each session the notes were transcribed onto the computer and impressions of the events were written.

The third participant, Dean, was observed at a ball field and lounge over a four day period (approximately eight hours). The softball team was introduced to me and it was

explained to them that I was interested in seeing how Dean "got along" with the group. I would observe Dean from a bleacher seat approximately ten feet away from the team's bench. While at the ball field, notes were taken, but at the lounge I did not take notes. This was because it was felt that the proximity of the team to me (at the same table) was too close and the team may have altered their interactions with Dean if they felt their behaviors were being recorded. Following each session at the lounge, I immediately noted my observations and impressions. After completing the observational periods, I conducted the interviews.

Interviews

By obtaining the interview data after the observational descriptions were made, the perceptions and opinions of the interviewees did not bias my interpretation of the events I observed. The prior observations, however, did allow me to place questions within contexts that were relevant to the interviewees' experiences. Therefore, I was able to glean more specific information by understanding and acknowledging the people, places, and behavior described in the interviews, because of previous experience with them during the observations. It is believed that this shared understanding between participant and researcher also allowed aided in developing rapport and creating a relaxed environment in which the interviews took place.

A open-ended interview format (Patton, 1990) was chosen for the interview portion of this study. This allowed for some structure and consistency as well as an opportunity to follow the lead of the participant and explore new differing statements. All interviews for the staff contained the same types of content : background information; professional and personal experience; perception and observation of events; and opinion of cause and effect. Interviewing techniques included: acknowledgment, paraphrasing or repeating of statements, and probing questions to elicit more specific information.

Data Analysis

Observations

In order to clearly describe what was being observed terms of reference were established prior to data collection (see Appendix C). At the end of each day, the coded data for Dana were tabulated according to the prescribed definitions. At the end of the total period of observation all of the frequencies for each code were aggregated and proportions were then tabulated by use of a paper, pencil, and calculator. Observations of Dana were also described in a narrative form in order to capture the nature of the environment in which the interactions took place. Narrative descriptions and accompanying impressions of the interactions facilitated my understanding and interpretation of events observed. Recollections of the physical environment the tone of the voices, the expressions on peoples faces, and the subtle reactions of the participants helped to clarify and elucidate the actions and interactions.

Interviews

The interviews were conducted in this study in order to enhance the descriptions and the impressions of the social interactions that I observed. The purpose was to provide a triangulation between existing knowledge of social interactions, observations of social interactions, and perceptions of social interactions. For the present study, these interviews were subjected to an analysis procedure advocated by Colaizzi (1978).

Data analysis began with transcribing each participant's interview into written format. This was done by a paid transcriber and then checked against the original audio-taped recordings by the primary researcher. The transcriptions were then read several times by myself and prominent words, phrases, sentences, and themes were highlighted and noted in the margins of each document. My in-depth prior experience with two of the participants and my observations and rapport established with all of the participants made it easier to interpret and understand the context and meaning of the interviews. The interviews were then edited and segmented into statements relevant to the topic that seemed

to express separate ideas. To assist in assigning separate meanings to certain statements, a paraphrased meaning was first ascribed to each statement that would help clarify the main theme or themes of the statement. Then an accompanying thematic descriptor (s) were assigned. This process was referred to as establishing "First Order Thematic Abstractions" of each participant's interview. This was done for all of the protocols separately.

The themes generated from each participant's interview were then clustered together into "Second Order Thematic Abstractions." This second stage of data analysis began the synthesis process where clusters of themes that were common for each protocol were aggregated. These clusters of themes were then referred back to the original protocols in order to validate them. This was done by checking to see whether themes may have been omitted, unaccounted for, or negated by anything in the protocols. Following this, themes were then amended accordingly. The final step in the data analysis process involved the development of "Third Order Clustered Themes." This is a step beyond the second ordered thematic abstractions and was presented as another way of defining and summarizing the experiences and to elucidate the common themes across all participants .

The following chapter presents the results of the observations and interviews.

Chapter IV-Results

Dana's Story

Background Information

Dana is a 58-year-old woman who currently lives alone with her cat in a basement apartment that she rents from the Parkview agency. The apartment is attached to a group home where she previously lived for 8 years. She is supported for functional life skill training and volunteer vocational training by Sue, her one-on-one worker. Dana depends on Sue for transportation, assistance with grocery shopping, assistance with budgeting, cooking, and other home based projects. Dana had previously lived in two other group home situations following approximately 40 years in a provincial institution. Dana has family that do not live in her home town, but with whom she maintains consistent contact.

Dana is a ward of the Alberta government and is under public guardianship protection. Because of the public guardian's policy on research and evaluation, written background information was not available to me. Dana is an attractive looking older woman who has a number of very interesting and endearing qualities. She is a woman who appears to be anxious and happy to make new friends and acquaintances, which may be the reason that she agreed to participate in this research study. Dana has an easy rapport with her worker and moves through the community with confidence and ease. She is well prepared in advance either through her own memory of what she needs to bring on an outing, or by the verbal prompts of her support worker. Once in the community, Dana appears to take the lead into places of business and is able to access the bank and the farmers' market without her support worker. Dana attends church independently and participates in a integrated seniors drop in and segregated leisure program with or without support. In a continued effort to gain rapport with Dana, I had several visits with her both in and outside of her apartment prior to data collection. Dana may be described as having a mild mental disability and some emotional difficulties. She is unable to read but provided

her verbal assent and signature when the letter of informed consent was read to her and the study explained.

Coded Observations

As previously mentioned, Dana was initially observed using a data collection sheet in the community according to predetermined terms of reference (see Appendix C). Data from coded observations of Dana showed that she interacted with 45 individuals in total. Interactions with strangers accounted for the majority (44%), followed by interactions with clerks (35%). Interactions with friends accounted for 13% of the total and interactions with co-workers (nondisabled) accounted for the least number of interactions (.07%).
Of this total number of interactions that were coded, 51.1% were initiated by Dana, 8.8% were initiated simultaneously by Dana and a clerk, six 13.3% were initiated by a clerk, 4.4% were initiated by the staff, 11.1% were initiated by a stranger, 2.2% was initiated by myself and in four interactions (8.8%) I was unable to determine who initiated.

In order to characterize the nature of some of the interactions observed, proportions were calculated for function of contact between Dana and her community. Of 45 coded interactions, 24 (53%) were found to be social-verbal in nature, 10 (22%) were functional, 10 (22%) were social-nonverbal, and one (.02%) was indeterminable. It was anticipated that there would be three types of settings in which interactions took place: a place of business, the neighborhood around Dana's home, and the community at large. It appears that the place of business involved the majority of interactions coded (73.3%) while the community accounted for the balance (27%). No interactions were noted in Dana's neighborhood during the time her interactions were coded and observed.

Dana's dependence on strangers for social contact was clear from the data. Her neighborhood could not provide the stimulation of consistent and predictable human contact until she utilized the community's generic services. Dana'a interactions were primarily social in nature and she initiated most of these contacts with others. The repetition of utilizing the same places of buisness facilitated the perpetuity of these interactions since

many of the people that Dana met knew her at least by sight. These community members responded most often with verbal acknowledgement though nonverbal responses to Dana's many initiations were also available to her.

Narrative Observations and Impressions

Dana's neighborhood was generally devoid of people on the streets during the times she was observed. As we walked through the community and as we approached people on the street, Dana looked eagerly in their direction. They always looked at us and smiled, if Dana was able to engage them in eye contact. It appeared that the community responded very positively to initiations by Dana, with pleasant social conversation, smiles, eye contact, and interest in the content of her conversation. For example Dana told two bank clerks (who knew her by name), that she was going on vacation, and they asked her details of her holiday and wished her a good time.

Dana blended in well with her small community and did not appear to have a disability, but she tended to miss some subtle cues such as waiting her turn in line, and became confused if a routine was somehow changed. At McDonalds she offered a coupon without understanding that it was a two for one coupon and that she could get two pizzas but had to pay for the first. The McDonalds' employee tried to explain the situation directly to her. At this point it may have become apparent to the employee that Dana required assistance, but if so it did not appear to change the employee's attitude or disposition toward Dana. Even when I tried to intervene to explain, the employee continued to direct her conversation to Dana alone.

Dana was fairly independent in the grocery store because Sue, her staff, had drawn a color coded map of the inside which Dana used in conjunction with a pictorial list. Unfortunately, the grocery store had just gone through extensive renovations so the map was no longer applicable. As a result, Sue spent more time looking for items with Dana. She also helped her make choices and gave suggestions for items that Dana might need. Dana pushed the cart herself and picked up items in the store independently after prompting

from Sue. The other shoppers did not seem to pay much attention to Dana or her staff but concentrated on their own tasks. The clerks were more aware of Dana than the shoppers and were more sociably responsive to Dana's gaze or initiations. This was especially true of the female staff and the older male staff, but not of the young men stocking shelves. When the clerks interacted with Dana they spoke directly to her and not Sue. This was probably because Sue tended to separate herself geographically from Dana during these encounters. Even when Sue was close to Dana, for example, behind her in the check out line, the clerk maintained her interaction with Dana directly. This was true of every place of business except for the pharmacy. At the pharmacy, the staff initiated the interaction out of necessity, explaining a medication problem. The pharmacist directed her instructions about the medication to the staff, likely because the staff had begun the conversation.

In the farmers' market, the atmosphere was more relaxed and sociable than other places of business. Dana walked through the market with confidence and initiated contact with all the people she recognized. Most of these were elderly ladies and they responded to her by smiling and saying hello. Dana would again venture that she was going on holidays, and they would respond to her kindly, and then go on to discuss work or church. Dana mentioned that "another" person (meaning me) was with her that day to which the ladies would respond with smiles and nods of acknowledgment. Dana approached a flower vendor who thought that Dana was there to pick up some flowers that had been ordered by her staff. Dana immediately understood the confusion and told the vendor that she was not there to pick up the flowers. The vendor, then asked Dana to relay a message to the staff to which Dana agreed. Afterward, Dana ordered a hotdog without waiting until the vendor finished with his customer, sort of "butting in" to the conversation. The vendor finished with the other customer quickly and immediately took and filled Dana's order and then asked what I would like. The vendor directed his glance and conversation to Dana directly as did another vendor who spoke to Dana when she lingered long enough at a table. If the vendor initiated small

talk with Dana, she would murmur something and then move away quickly, perhaps not wishing to engage in a conversation that she did not initiate.

Dana and I went to have lunch at a seniors drop-in center in her town. There were about 150 people there, seated at long tables and served by volunteers. They knew Dana well there and greeted her as she came in. Dana approached a few people to say hello and although she interrupted their conversations with others, they smiled and greeted her warmly. We sat with other people with disabilities and their staff, who also went on these lunch days. As the ladies served, they said hello to Dana and the other clients and asked them what they wanted to drink. Dana divided her conversational time between me, her acquaintances with disabilities, their staff, and an elderly woman without a disability across from her. The woman across from Dana asked her if she lived in town, and Dana told her that she lived in a suite near "Mike" and that she had an animal. The lady responded with polite conversation even though she didn't know who Dana was talking about. Introductions of guests were made by the host, and Dana yelled that they had forgotten that she had brought a guest, me, and I introduced myself. The gentleman acknowledged me, Dana, and the other clients, referring to them collectively as "being from the group home".

A Summary of Sue's Interview

Sue is a 33 year old woman who has worked for the Parkview agency for four years and with Dana for a year and a half. Sue has had approximately 15 years as a rehabilitation worker but has never received any formal training through college or university. Sue has received inservices and workshops, though, on a number of topics related to working with people who have mental disabilities. Sue's experience in this field has included work in institutions, group homes, and community outreach programs. She supports Dana out of her home approximately 20 hours per week. Table 1 presents my Second Order Thematic Abstraction of Sue's reported experiences and perceptions of social interaction between people with mental disabilities and community members. The Second Order Thematic Analysis combines all of the First

Order Thematic Abstractions into clustered themes that reflect similar ideas, and provides a generalized description for each clustered theme. The numbers underneath the thematic clusters denote the initial themes from which the cluster is formed (see Appendix D).

Sue's work with Dana allows her to maximize Dana's functional living skills while supporting her emotional needs. Sue's belief in Dana to be able to overcome her institutional upbringing reflects her obvious respect and fondness for her. She believes that as Dana's independence develops her own role will diminish, but that is a judgment that requires evaluation from both herself, Dana, and their agency. Sue sees Dana's ease in the community as a being facilitated by Dana's age as well as a small town acceptance of people who might need more time and consideration than a bigger city can afford to give. Sue's services to Dana include social skill coach, when Dana's need for attention may alienate the people she interacts with. Sue readily points out that Dana has several qualities that would make her a welcome addition to a social circle.

Despite the unusual experiences Dana had growing up, Sue recognizes that Dana is more alike than different from her community members. They all share the same basic need for favor and encouragement. Sue is respectful of Dana's decision-making process and will offer advice to deal with difficult social situations, but Sue will not intervene on Dana's behalf. The relationship between Dana and Sue is one that is necessary for Dana in order for her to succeed in the community. It is a relationship that is required to supplement Dana's natural support system.

Table 1

Second Order Thematic Abstraction of Sue's Interview

Thematic Clusters	Generalized Descriptions
1. Small town support (1, 2)	A small town is more geared to helping and understanding people with disabilities than a larger city.
2. Staff mediation-understanding client's needs, support, agency support, assistance (5,6,7,8,9,11,12,14,15,16,)	We understand who Dana is and what she needs and I need to directly aid Dana in order for her to integrate smoothly into the community.
3. Community misperception (3)	In many ways Dana's needs and wants are no different from anyone else's, but because she is an older adult she is not as well regarded as the young.
4. Positive regard (4,13,10)	Dana has many qualities that should make her a welcome member of this community.

Dean's Story

Background Information

Dean is a 19-year-old man who lives at home with his parents and is a client of the same Parkview agency as Dana for his community options program. Dean's day program also consists of functional life skill training with a one-on-one worker but has more of a community exploration and work experience component to it. This is because Dean and his family are preparing for his transition from his family's rural home to community-based supported living.

Dean was working part time at a zoo but recently had his community options program changed to focus on community awareness and social integration. This was directed by Dean's parents who are strong and active advocates for their son. In an interview with Dean's mother, she reported that Dean was born in Edmonton and that there

were no difficulties with the pregnancy or birth. Dean's parents noticed that Dean "made strange" early but followed the lead of his older brother for many of his developmental skills. Dean showed an interest in music, pictures patterns, and spinning objects. Dean was subsequently diagnosed with pervasive developmental disorder (autism). He attended a regular E.C.S. program with an aide and was in special education for grades 1 to 12. Dean attended junior high school for 1 1/2 years and high school for 4 years. Dean learned functional reading and was particularly good at math in his special education program. In elementary school the family acquired a specially trained "canine companion" who accompanied Dean to school until junior high when Dean decided that he preferred to go without his dog.

Dean exhibits the stereotypical type behavior associated with autism. This may also include self-injury and aggression although these behaviors are rare. Dean's adaptive skills suggest that he will still require supervision both vocationally and residentially, but his social skills are well developed and are beyond what would be expected given his difficulty with language. Dean is a warm and engaging man, who seems to spend much of his time observing others to learn the cues necessary to function socially.

Narrative Observations and Impressions

Dean is a member of two baseball teams. Rather, it is more accurate to say that his support staff is a member both teams, and brings Dean to the games with her. During his time with the first team, it was observed that Dean mostly sat on the bench with some of the children of the players. He held a baseball and as he got up to play catch with his staff, he spoke to a little girl. He then threw the ball toward her, which hit her. Immediately she started to cry. His staff quickly encouraged Dean to come play catch but no one made a big deal out of the incident. Dean understood that he did something wrong, and when directed, he said sorry to the little girl after playing catch. He then asked other team members to hit him on the arm with the ball to which they playfully laughed and teased him. By the time the game got underway, the players have all greeted Dean and looked and spoke directly to

him. His staff did not remain by Dean's side for long and the players chatted with him easily: "Hey Dean you're on my smokes" and "Dean do you have my glove"? are examples of the easy banter in which they engaged. Dean would initiate to them as well, speaking in repetitive phrases, sometimes in context and sometimes not. "That's dangerous" he said referring to the ball incident with the little girl. The team responded to him by looking at him directly, by giving him direction or by simply acknowledging his presence.

It is after the ball game and the group went to the local lounge. As they sat and hashed out the details of the game laughing and joking with each other, Dean sat with them, rocking and laughing too. They joked with Dean and occasionally talked to him about some friends they have heard Dean or his staff talk about. These friends are actually former classmates of Dean's from about ten years ago with whom he has recently been reunited. There was a running joke about Dean wearing shorts and they teasingly asked him when he will finally don a pair. The woman sitting beside him is the same mother that sat with him previously on the bench at the ball field. She didn't speak to him, but then she didn't speak to many people on the team and was very quiet. Dean's presence doesn't seem to bother or excite her. The entire gathering had an even tone about it. Dean's presence didn't seem to change the behavior of the group either way. They together are cohesive, are friends, and are teammates with or without Dean. Dean is allowed to be a part of the group as simply another member. Some are outgoing, some are quiet, and one has strange behavior, a team nevertheless.

On another occasion, Dean and his staff played with the second ball team. Most of these players were younger, closer to his staff's age and were friends of hers from high school. Dean was a little calmer on this night, and I arrived as their game got underway. Dean again sat on the bench with the team, and the players spent a lot of time joking with him and responding to his conversation. Dean ran out on the field three times. The first time he shook the hand of a young boy that was up to bat. His friend Sara was behind the

plate and told him to go sit down, but the players on the field were jovial and one yelled "management", which got a few laughs. The second time Dean ran out he yelled something about a bat. It was not his team's turn to bat, but his move was interpreted by another player that Dean wanted to bat. When it was his teams' turn to bat, he finally got his chance and was prompted out to the field by members of the group. Dean was encouraged by the team as he swung, and finally hit the ball and ran to first base. He came off first base to sit back down at the bench and the players on his team congratulated him saying "good hit Dean". As the game wore on, Dean approached one of his teammates and touched his face saying "cut". His team mate tried to respond. Before he had the chance to however, Dean immediately turned his attention toward two women in the opposite direction. Although Dean initiated the interaction and his team mate eagerly responded, Dean's quick attention to another person left his teammate trying to encourage a connection, but without success.

This second team also went to the bar after their game. This was a louder and more boisterous group than the first, although a couple of the women and men were very quiet and mostly listened or watched the game on TV. Dean was quite excited on this night. Between moments of attention and interaction with the group, he yelled, rocked, picked his nose, and swore. The team largely ignored these behaviors and his staff sat three or four people away from Dean. Members of the team tried to ask Dean questions or talk about what he was interested in, such as his birthday. At one point the team toasted Dean's birthday with a clinking of the glasses. Later in the evening, Dean ran up to the counter by himself to order. I was informed by a few of the players that he likes the chicken. Dean jumped around a little, but the rest of the restaurant patrons did not seem to notice or care. Even the folks beside us who could clearly see and hear Dean did not stare or say anything.

It was a fun, happy, and most of all very comfortable gathering. This group tried to make me feel welcome, but I was clearly more of an outsider than Dean. They seemed to genuinely like him, wanted to be friends with him, and wanted to include him. They

were not rehabilitation trainees, they did not help him do anything, and they did not direct him not to. They simply let him come in and stay without conditions. This seems to me to be a remarkable phenomenon. This is an attractive, intelligent, confident group of people for whom you would think that image would be everything, especially in a small town. There was distinct lack of design here. Nature was taking its course.

Dean's mother told me that the team asked Dean's whereabouts when his staff did not bring him one evening. It is easy to see that Dean has been readily and easily accepted as a part of the group. When Dean starts to rock or vocalize, he is largely ignored by his social circle. Actually it is clearer to say that his behavior is largely ignored but that he is not. Sara, seemed to take the most interest in him, directing his behavior ("Dean don't pick"), engaging him in conversation and greeting and saying good-bye to him. People from opposing ball teams did not interact with Dean but did not seem to mind his presence. Passersby also did not take notice of Dean, perhaps because he blended in easily with the group with his cap and jeans. Only when the team is playing in the field and Dean is on the bench might you notice that anything is amiss. He rocks and groans alone for a few minutes between the innings. Then as the group charge back to the bench they laugh and tease each other and chat. They envelop him.

A Summary of Sara's Interview

Sara is a non-disabled young woman in her early twenties. She is married, works as a clerk in a local mall and is also a friend of Dean who plays on both of his baseball teams. She was born and raised in the town in which the study took place, and remains friends with many people from her high school including the support staff for Dean. Sara is active in both summer and winter community sports and has had no formal or informal training in work with people with mental disabilities. Table 2 presents my Second Order Thematic Abstraction of Sara's reported experiences and perceptions of social interaction between people with mental disabilities and community

members. The numbers underneath the thematic clusters denote the initial themes from which the cluster is formed (see Appendix E).

Sara's perspective of Dean's integration into her community and group of friends is a positive one, and one in which she seems to take pride. She has an active interest in the welfare of Dean and in establishing a personal relationship with him, although she still requires the mediation of his staff in order for this relationship to endure. Sara's observations of Dean with her friends suggests a brief introductory period and quick acceptance of Dean and his repertoire of unusual behavior. She explains this acceptance by her team, as due to a trust in Dean's staff and their prior exposure to people with disabilities in school. Dean's personal contributions to the group also explains their fondness for and their acceptance of him. In her observations of Dean with community members, Sara stated that even strangers seem to tolerate Dean's initiations towards them. At first strangers might not know how to react or might react in fear. Continued exposure as well as modeling by Dean's staff and friends might have helped to overcome this initial uncertainty by others.

It seemed that support of Dean was transferred from his staff to Sara without a formal agreement, plan, or program in place. This support of Dean, by Sara, was likely borne of her own interest in Dean as well as necessity, since his staff was an occupied player during the ball games. Sara's feeling that her team missed Dean when he wasn't there and used him to fill in for an absent player, illustrated his belonging to this group and their acceptance of him as a member.

Table 2

Second Order Thematic Abstraction of Sara's Interview

Thematic Clusters	Generalized Descriptions
Staff Mediation-connection to community, assistance, modeling (1,3,5, 6,10,12, 22, 25, 26)	The staff have actively tried to connect Dean with the community and play a large part in helping him navigate his way through relationships.
Belongingness (13,16,18)	Dean is more and more becoming a part of our group and the community in general.
Initial Uncertainty (4, 10, 21)	At first it is hard to know how to respond to Dean.
Desensitization (4,7,6,11,15,)	More and more time with Dean increases our comfort level and enjoyment of him.
Reciprocity (8, 9, 14, 17, 18, 20, 24)	Dean gives back to me and the team in many different ways.
Community Modeling (10)	We need to watch each other to know how to behave with Dean.
Natural Support (19, 21)	At times staff intervention is not necessary and we can direct and help Dean on my own.
Client Initiation (2, 22, 23)	Dean will often make contact with others without facilitation by anyone.
Positive Regard (8,9,11,14,20)	There are characteristics of Dean that make him great to be with.
Community Tolerance (22, 23)	I haven't noticed any negative community reaction to Dean, despite some unusual behavior.
Community Misperception (27, 28)	Ignorance has led to a misunderstanding of the circumstances of how these people live.

Dave's Story

Background Information

Dave is a 32 year old man who lives in a six-person group home operated by the Riverside non profit agency in a small city. He has a one-on-one worker for a 30 hour per week community options program and for 24 hours of residential supervision. Dave resided with his grandmother until he was 6 years old, at which time he moved to "Springfield Center," an institution, where he lived for 12 years. In 1984 Dave moved out of the institution to his group home where he resides with three other men and one lady.

Dave graduated from a segregated special education school in June, 1988 and began attending his day program in September, 1988. Initially, his program consisted of a full day indoors, ostensibly participating in "developmental activities" that included sorting nuts and bolts and putting pegs in a peg board. Dave spent about 80% of his time in this program engaged in self-injury or rocking in a chair. In April of 1993, Dave began purchasing 30 hours per week of individualized funding so that a community based program could be designed for him that included community awareness and functional skill development. Dave was given this funding in hopes of decreasing his severe self-injury.

Dave has participated in several activities through his new day program. These are constantly changing to accommodate both Dave's and the community's needs. They have included: recycling, swimming, bowling, going to the park, going to the library and going out to a restaurant. Volunteer sites for Dave have included laundry jobs at long term care, folding pizza boxes or light cleaning at Boston Pizza, and his current position of folding napkins at a local diner. Dave learns by hand-over-hand, prompting, and modeling.

In terms of his skills, Dave is able to eat and drink independently, although he can be messy at times. He initiates going to the bathroom, however he needs assistance with fastenings. Dave will at times respond nonverbally with a small head nod when spoken to, is able to dress himself with assistance, but can undress independently. Dave wipes his

face and washes his hands with verbal prompting. Dave will initiate taking chips out of his bag,

will put money in a vending machine with staff assistance, and will push a button to make a selection. Dave will push the elevator button when getting on the elevator, open some doors, and has learned to push fountain tap to get his pop at Boston Pizza. Dave can pour his own juice and place towels on rack with verbal prompts. Dave will assist with putting clothes in his closet, and will pick up dirty laundry and place it in front of washer. He will carry his own tray unassisted at the cafeteria, and can turn music on and off using a microswitch. Dave can sign the words "please" and "drink". He will gesture or pull staff toward or away from area to indicate what he wants. Dave sometimes lets people know that he is not comfortable or dislikes something by becoming agitated or self abusive.

Dave can be extremely self-abusive. He will hit his face with the heel of his hand or with a closed fist, which can result in significant damage to his face. Dave will also bang his head backwards and has in the past put his head through a wall during this behavior. There is an approved behavioral program in place, and the same procedure is used by all staff who work with Dave. The program includes the use of a large helmet that prevents Dave from striking himself. Dave may be described as having a severe mental disability with features of autism.

Narrative Observations and Impressions

Dave is usually picked up by Sandy from his home. Dave is often waiting on the couch, rocking. You can tell what kind of a night and morning he has had by the intensity of the bruises on his face, as a result of his punching his cheeks with his fist. Dave eagerly boarded the van and took his preferential place in the back seat, although he could sit anywhere since there is only Sandy, him, and me on board. One of Dave's favorite activities is to drive and so we drove around the city for about 15 minutes before arriving at our first destination. At stop lights Dave would jump up slightly in his seat, which has been interpreted by Sandy as a request to keep moving. We began at the recycling depot,

which is attached to the building of a vocational agency for the disabled. Dave and Sandy disembarked from the van with recycling from the group home in hand. When Dave has the chance he will often walk or stand with his fingers pressing on his ears. With a garbage bag in one hand, he could only do this with the other. With her prompts, he took Sandy's arm and was led to the recycling receptacles. The staff of the other agency smiled toward Dave and exchanged hellos with Sandy. Other clients of the agency were also working around the recycling area and smiled and said hello to the staff but not directly to Dave. These clients are less mentally disabled than Dave and may have perceived themselves as being in a different 'club' than Dave's, at a higher level on the continuum between staff and people with mental disabilities.

We arrived at Dave's volunteer placement, Sylvia's small diner. One by one the regular clientele came in to the restaurant, each greeting the owner. They are an older group, mostly retirees and a few businessmen who are well known to each other. They bought their coffees and took their places at their table, looking in the direction of Dave and Sandy but never making contact. Dave finished his task and moved to receive his reward. After choosing a drink with the help of Sandy, she put the money in his hand to give to his employer. The employer took the money but did not speak to Dave directly. As Dave enjoyed his juice and chips, two tables away the coffee club chatted and laughs and discussed the days events. Dave and Sandy were ignored except for a few glances and smiles. Sandy informed me later that this group sees Dave every week and indeed the following week the same group arrived and the routine began again. The employer remarked at how well Dave was doing to his staff and a woman with the coffee group nodded her assent. It was not clear whether the employer was referring to Dave's work habits or behavior or health but she spoke with the confidence of someone who knows this man well. Although Dave did not share in the social life of this domain, he was part of it just the same. His contribution was acknowledged and his presence accepted, even if it was in parallel with this peer group rather than as a member.

A trip to the mall in Dave's town was a somewhat gloomy experience. Like so many older malls in small towns, this one was dark with cheaper stores and a lot of cigarette smoke. The carpet had recently been changed, which helped the look of the mall, but it still could not escape the dreary feeling it projected. It did not seem to make a difference to the hundreds of shoppers that take advantage of the larger department and discount stores. Dave had been to this mall often in the last five years. As we walked through the narrow aisles of the Wal Mart, Dave brushed against a woman. She said nothing and looked away. The people of the mall tended to look quickly at Dave or avert their eyes completely. It is an inexpensive venue for meeting the goals of integration and he enjoyed walking through and eating his lunch at the old food court. Dave sat at a table waiting for Sandy to get his meal. She informed me that often Dave will go with her to the counter to buy his own fries or hamburger, but if he is hungry or impatient it is easier for Sandy to get it for him quickly rather than risk a "behavior." On this day we were joined by another client and staff. We sat close to two older men. One continuously looked at Dave with a kind smile on his face while the other ignored us completely. A former staff of Dave's came up and said hello to him. She asked him how he is and Dave looked at her, without expression. As we walked through the mall another woman said hello to Dave by name but I am unsure as to her role in Dave's life. Sandy told me that people will often say hello to Dave. This does not surprise me given Dave's years in the community and need for staff. Dave and Sandy bought a bag of chips in a store. Sandy brought Dave to pay but the clerk was unsmiling and directly interacted with Sandy. At the lunch counter the clerk greeted Dave by name "hi Dave" but then also relied on Sandy for the order. While at lunch we were joined by Sandy's husband who took a seat beside Dave. The conversation was jovial but did not include Dave in any way.

We arrived at one of Dave's favorite places, a museum that also has some simple amusement rides. We waited to have a ride in an old four seater antique car. When it picked us up, Sandy put Dave in the front seat with the driver while we sat in

the back. The driver looked uncomfortable but he was polite and smiled at Dave. The driver and the staff struck up an easy conversation about cars while we drove around. Of course this is Dave's favorite activity. As we drove, Sandy remarked about how much Dave liked the museum and what a good time he was having on the drive. "That's why we're here" smiled the driver. He reminded us that there was a donation for the ride. When we stopped, the staff gave Dave the money to put in the driver's coffee can. Sandy helped him do this hand over hand. The driver told us that there would be more rides in the afternoon. We thanked him. Later in the afternoon we came back to the museum. We went outside to the amusement rides. The ticket taker Sandy and invited her and Dave on the first ride. She had met them before and knew that Dave enjoyed the movement of the rides. The ticket taker invited Dave and Sandy to continue after the ride was completed, which they did for about a half hour. She and Sandy talked together, and Sandy remarked on how Dave enjoys the rides. The operator smiled. At the restaurant in the museum, Dave gave the clerk the money for his food but the cashier gave the change to Sandy. A woman came to wipe our table and smiled at us. We took another ride in another old car with a different driver than the morning. Again, Dave sat in the front but this driver was more relaxed and spent a lot of time looking at Dave and smiling. Dave put his hand on the steering wheel. The staff did not notice and I remarked that he liked to put his hand on the wheel. The driver said that he could steer around Dave's hand and that maybe "he" would like to hear the horn. As the driver beeped the horn he took Dave's hand and helped him push it. The staff remarked that Dave liked this and that seemed to please the driver. He also echoed the first driver "that's what we're here for" but did not mention the donation. He offered to drive us to our car.

We went back to Sylvia's diner to continue work, and Dave sat and began to fold napkins again. A customer came in, and the staff said good morning . She smiled at Sandy and Dave and watched them work. Soon one by one the group filed in and took

their seats at their table. Dave began to clap loudly, and two of the group looked at him and smiled. Then they looked away. It was not yet necessary to further include Dave and Sandy. The community members remained tolerant, but comfortably distant in this small environment.

A Summary of Sandy's Interview

Sandy is a woman who has worked for the Riverview agency for approximately 18 months and with Dave for one year. Prior to this she had no experience working with individuals with disabilities but saw them frequently through her last position as a retail clerk in the local mall. As a result of this contact Sandy applied for a job with the agency working on a team with several different clients, and then applied to work with Dave individually when the position became available. She is approximately 40 years old. Table 3 presents my Second Order Thematic Abstraction of Sandy's reported experiences and perceptions of social interaction between people with mental disabilities and community members. The numbers underneath the thematic clusters denote the initial themes from which the cluster is formed (see Appendix F).

Sandy expressed a genuine affection for Dave and a need to have him live the most rich of experiences in a community setting. She stated that before she started working with Dave she was herself a "community member" and saw him repeatedly in the mall where she worked. She envied the people who used to work with him. Now as his staff, she is constantly by his side, interpreting his needs, and facilitating his voyage in the community.

Sandy seems to be able to anticipate the reaction to Dave, and can then modify that reaction. This may include circumventing a negative response by interpreting an initiation to a wary community member. It may also include removing Dave quietly from a provocative situation if he begins to become agitated or self-injurious. By these actions, Sandy believes that she is cultivating not merely an acceptance of Dave, but a necessary trust in her abilities to control him. Sandy's understanding of Dave's needs and

construction of his world to meet those needs includes an invitation to the community to participate. This invitation has been accepted if only for a few moments by many of the people Sandy and Dave encounter during their days together.

Table 3

Second Order Thematic Abstraction of Sandy's Interview

Thematic Clusters	Generalized Descriptions
Staff mediation-assistance, community perception, education, connection, understanding needs, modeling (3,4,5,6, 7,8, 10, 11,14, 16,17,19, 20, 22, 23, 26, 27, 28, 31, 32, 33)	I am there to help Dave when he needs me in a variety of ways and it is I who is his link to the community.
Community Misperception (30,34)	Some people do not understand who Dave is, who I am, and what our relationship is.
Initial Uncertainty 6,14,17,18,25)	There is usually fear and hesitancy when encountering us for the first time.
Belongingness (12, 9)	Dave is becoming more and more an accepted part of this community.
Reciprocity (12,15)	Dave and I give back to the community as well as take from it.
Client Initiation (2, 17)	Dave will go up to people and try to make contact with them without it being facilitated by a staff.
Desensitization (7,21)	More time and experience with Dave directly, helps people to better accept him.

A Summary of Sylvia's Interview

Sylvia is a member of the community and is also Dave's employer in his volunteer job. Sylvia has operated her diner for approximately 15 years. She

previously worked in another province as a caseworker for the physically handicapped and welfare recipients. She began to accept persons with disabilities into volunteer positions in her diner in 1987 through the local special education school. Sylvia is a member of the chamber of commerce, volunteers with Special Olympics, and has sat on the Board of Directors for the agency that Dave belongs to. She also volunteers for their fundraising bingos. She is in her 50's. Table 4 presents my Second Order Thematic Abstraction of Sylvia's reported experiences and perceptions of social interaction between people with mental disabilities and community members. The numbers underneath the thematic clusters denote the initial themes from which the cluster is formed (see Appendix G).

Sylvia's perspective of the social integration of people with mental disabilities and of Dave in particular seems to combine the philosophical with the pragmatic. She seems convinced as to the necessity of staff in this enterprise and the need to balance the comfort of her clientele with the use of the restaurant by the agency. Sylvia's relationship with the staff directly, appears to be a necessary variable in the success of the volunteer program. The reciprocity that has emerged between business and charity is played out on a daily basis in these volunteer jobs. The "regular" clientele have come to accept and perhaps welcome these volunteers. They have become part of the culture of Sylvia's restaurant even though they are still segregated by staff. Despite initial uncertainty, through the continued presence of the volunteers with disabilities, a process of desensitization has occurred. This seems to be an environment where the social modeling by staff and other patrons help the customers learn how to co-exist with the volunteers. Even when unpredictable events such as an initiation by a client to a customer occurs, it is at the very least tolerated and at best, welcomed by the recipients of these overt gestures. Sylvia was clear in her belief that the integration of people with disabilities in her diner may be an isolated success. Sylvia feels that the severity of her volunteers' disabilities would keep her and other entrepreneurs from taking over their support from staff. It does not seem to

be an issue of specialty on the part of the staff, but an issue of time and energy that would prevent a businesswoman like herself from becoming a rehabilitation worker.

Table 4

Second Order Thematic Abstraction of Sylvia's Interview

Thematic Clusters	Generalized Descriptions
Staff mediation-assistance, consistency, reciprocity, safety (1,3,4,10,17,15,19,21,23,24)	The staff are key for this to be a successful integration experience and mutually beneficial.
Knowledge of individual's needs (2, 18)	My experience with these individuals has helped to know their needs and abilities, but this may not be true for everyone else in the community.
Belongingness (11,12,13,14,20)	At this restaurant, the individual and their staff are part of the place now. They are needed and welcomed and accepted as anyone else.
Initial Uncertainty (5)	We didn't know what to expect from having these clients here.
Desensitization (6,7,22)	Time, repetition and experience leads to a comfort level with these people.
Community Modeling (8)	The customers look to each other for direction in how to behave.
Client Initiation (9)	Some of the clients initiate contact with the customers.

The following chapter presents the discussion of the results. The third order abstraction of common clustered themes across all interviews are utilized as topic headings (see Table 5).

Table 5

Third Order Abstraction of Common Clustered Themes

Third Order Themes	Common Clustered Themes
Staff Involvement	Assistance Mediation Consistency Connection to Community Modeling Reciprocity Understanding Client's Needs Agency Support Safety Community Perception Education
Direct Experience with Individual	Desensitization Initial Uncertainty Belonging Community Misperception Community Modeling Natural support Understanding Individual
Individual qualities, not level of disability, are important	Reciprocity Positive Regard Client Initiation

Chapter V-Discussion

The goal of this study was to explore the social interactions between three adults with mental disabilities and their community members. The study had two methods of data collection. First, I conducted naturalistic observations. The purpose of these observations was to explore the actual behavior of adults with disabilities and the community. To provide triangulation and to augment the observations, interviews were conducted with two staff and two community members familiar with the aspects of these social interactions. The findings presented above will now be discussed. Three identified variables appeared to be important to the nature of social interactions between people with and without disabilities: the amount of staff involvement; the amount of direct experience with the individual with the disability; and the personal qualities of the individual, irrespective of their level of disability.

Staff Involvement

Across all interviews it was clear that in the perceptions of the participants, staff played a central role in the integration of adults with mental disabilities in the community. Clear themes of the use of staff in assisting and mediating between client and society emerged from the participants. The intensity and nature of the role varied only slightly between the cases and may have been dependent on a number of variables. For instance, Sue supported Dana less frequently than Sandy supported Dave, but Dana was far more able to access the community independently than was Dave. Dana, then, depended more on natural support systems and was observed to interact with a variety of community members for a variety of reasons without the help of her staff. However, Dana's dependence on Sue to help her plan and problem solve was as necessary for her success in the community, as was Dave's grasp of Sandy's arm.

Sue stated it this way:

"Because Dana has an emotional problem...with my program, most of it is just the organizational thing like anything from grocery shopping to whatever. As long as she's organized and knows what she's doing, she could just walk in and do whatever she has to do and walk out. But if she doesn't have that, she's lost....It keeps her together. It keeps her mind together. Some people need that."

Studies of social interaction in vocational centers have found that employees with disabilities tended to interact more with their job coaches than with non-disabled co-workers (e.g., Storey, Rhodes, Sandow, Loewinger, and Petherbridge, 1991). However during this present study, Sue was able to fade herself out of the direct interactions Dana had with the community. Through observations it would be appropriate to say that staff in this case only set the stage for these interactions to occur.

It was interesting to discover that even the community members that were interviewed relied on staff to facilitate the continued presence of the person with the disability in their lives. A paid staff was relied on by Sylvia to maintain Dave in her business and by Sara to maintain Dean in her life. Both Sylvia and Sara seemed able to take over the roles of the staff and were observed to enjoy their social interactions with Dave and Dean, but it was the staff who set the stage for these relationships to form. Perhaps if these community members had not been introduced to these individuals initially by a staff, the perceived reliance on the support of staff would not have been so pronounced. However it cannot be overlooked that if the purpose of these programs was to connect these adults to people in the community, then it appeared that in these cases they were succeeding.

In her interview, Sue discussed larger issues in Dana's life, including where she would live: "but I told them at the agency if she doesn't want to move, I'm not going to make her move, but if she wants to go, she's ready," implying perhaps that despite Dana's apparent independence and choice, it was still Sue who will make these decisions with Dana's agency. The question of course is whether client dependence on staff is a need, a

luxury, or a hindrance. There are advocates of integration who eschew the service agency entirely in favor of "natural supports" within the community. For example, Hasazi reported McKnight (1991) stating,

> It seems to me that the major action necessary for a service system to ensure community incorporation of people with disabilities is for the service system to get out of the way. Service systems represent an economic and psychic wall between the community and individuals who are disabled. (p. 539).

Sylvia, Dave's boss, might disagree. The staff ensured the safety of her volunteers with disabilities, facilitated and assisted in their work, and took care of problems as they arose. Sylvia, in turn provided a desperately needed community venue for the program, and in doing so built a loyal clientele. In her interview she discussed this unwritten contract:

> "I think its more important that the people working with them has a place to go where they can feel comfortable. For every client there's a worker...that's a big work force here in town. Looking from a business perspective too, its a big work force so if they like it here, chances are they'll come back with their families or just say it's a good place to go. I look out for myself too! Well so if I lose two customers in a year because they have something against being in the same place with handicapped, well I'm sorry. I get the other side of it. But having the workers coming in here and the clients working...there's a lot of programs going in here which makes my life a lot easier. "

The use of paid staff support has recently been criticized because they cannot be "true" friends, because they do a job that could be accomplished by the community, and because they maintain a "we" and "them" mentality between people with disabilities and people without disabilities. Yet it is clear from the present research that "staff" might simply be a moniker that describes a person who uses their own personal resources to meet the goals of their agency. The staff observed did not use any special technique, any

shaping, chaining, or reinforcement strategies to connect their charges with other people. Indeed it speaks to Mr. McKnight's point that the community at large could easily take over the job of "staff" because despite our knowledge of social skill training, it may only be necessary to bring people with disabilities into the community, sit them down, and invite someone to join in.

Schalock and Genung (1993) found that of adults with mental disabilities studied, those receiving formal services tended to be lower functioning and had fewer relationships with family, advocates, and neighbors then the higher functioning subjects. This of course implies and supports the supposition that staff inhibit necessary non-professional and non-peer contacts. However, data from my study showed that in the case of Dean and Dave who were both lower functioning, advocate and non-peer support were available to them through the facilitation of their staff. But their staff may have been limited in controlling the extent to which interactions were maintained. Personal skills in expressive language ability, turntaking, and comprehension may have impeded both Dave's and Dean's competence in sustaining a communicative interaction. The question, then, becomes one of subjective evaluation of the "goodness" of interactions between people with more moderate and severe mental disabilities and others. Does an acceptable interaction imply a longer interaction, or should such interactions be evaluated according to who initiates, who responds, and the conversational content?

Conversational dominance has in fact been previously described. Owen, McDonald, and Baine (1994) found that in staff-client interaction within a group home setting, staff accounted for the vast majority of initiations. This has indeed been considered an obstacle to social interaction among the mentally disabled. One of the problems may be, however, what staff interpret as appropriate or inappropriate initiations and which ones they then try to inhibit. Chadsey-Rusch (1992) believes that social skills are judged to be competent or incompetent by others and that competent skills are likely to be received positively by others whereas incompetent skills are likely to be received negatively by

others. From Sandy's recollections of Dave in the community, this may not necessarily hold:

> "We were walking down the mall and he didn't want to hang onto my arm, he wanted to go into one of the stores, but he won't go in alone, so I was walking down the mall waiting for him, I turned around and he walked up to this strange lady and gave her this big bear hug and I ran up to her and she looked...she looked like she was in fear and I said to her 'Dave is OK, he just wanted to give you a hug because he thinks you're so beautiful,' and she looked at me and she smiled like she just melted and it was O.K. then, she was fine."

The role of staff then, must adapt to the needs of the client and the situation from minute to minute and day to day. The recruitment of staff may have to change from hiring the professional with a bag full of programming tools, to hiring the sensible, assertive, community member who will help the disenfranchised become connected. According to Sylvia,

> "There's disabilities and disabilities. The ones that I have here are severely disabled. They could no more...maybe do something for a very short period of time on their own or you show them, but the majority can't so you take a lot of hands on, one-on-one helping."

But Sylvia's point may not be that the severely disabled could only survive in an employment setting with *staff* helping them, but that the severely disabled could only survive in an employment setting with *someone* helping them. Before becoming a staff, Sandy was a clerk in a store and now is paid for being Dave's support worker. Could she have provided the same experiences with Dave while being a clerk? Of course, because Sandy's gift to Dave is not a professional one but a personal one. The two have a relationship that is mediated by money only to the extent that Sandy is compensated for her time. But Sandy's minute to minute decisions of how she is going to connect Dave to the people in his town is directed by her own creativity, assertiveness, and willingness, not by

her status as staff. Although the people of the community put their faith in Sandy to take care of Dave, they likely only saw her as Sandy. She did not introduce herself to the community as Dave's staff and could have been his sister for all they knew. Therefore the question of whether staff impede the process of integration by not allowing community supports to take over may be irrelevant if the goal is community connection. Does it matter if the connector is paid or unpaid? It didn't seem to matter to the people who Dave and Sandy encountered on a daily basis, and it didn't seem to matter to Dave. Likely it mattered to Sandy though, because without the pay she may still be in the mall watching Dave and wishing to be his worker and Dave may still be rocking his days away in a chair between institutional walls. O'Brien and O'Brien (1992) suggested ways in which service professionals could better facilitate community relationships. They included: taking less of a controlling role with their clients; accommodating their client's individual preferences and needs; and encouraging contacts and relationships outside of the agency's own programs. Findings from the present study suggest that the staff involved have attempted to facilitate community relationships through planning around individual needs, facilitating contact with community members, and fading out of the interaction between natural supports and their clients when appropriate.

It is certainly the case that the disabled have moved from institutional refuse to a hot commodity in a scant 30 years. Funding as it presently stands in Alberta attaches certain moneys to the individual themselves, thus allowing for service agencies to vie for their business. As unseemly as this may sound, the present research might support the involvement of staff as the catalyst to integration rather than the cause. For example, both Dana's staff and Dean's staff introduced them to people in the community and helped to overcome the logistical concerns of integration (Dana finding her way around the grocery store, Dean joining a team) but then faded away to allow natural supports to take over. Dana was observed to interact directly with mostly clerks and strangers during her forays into her community and Dean was observed to socialize with his teammates directly without

the filter of his paid staff. Dave was never seen to initiate or respond to any interaction without the assistance of Sandy, however he was still known and for the most part accepted by the people in his work placement.

The question of whether staff actually hinder or help the integration process likely ultimately depends on the staff themselves. Of all the participants interviewed, only one, Sue, briefly mentioned the role of the agency in the integration plan. In fact, Dean's plan was more directed by his parents, Sylvia preferred not to work with the management at all and Sandy stated

> "I wake up in the morning as if it's an adventure. What are we going to do today...I think of it like that. How is Dave going to enjoy the day today? I don't think of how is the community going to accept Dave today?"

In summary, the data from this study suggests the need for staff to continue to work with these individuals with disabilities. The level of support required is governed by the individual needs and wants of each client, and changes on a minute to minute basis. The role of the staff though, is not as expert in the field of mental retardation. It is as community member who is able to skillfully facilitate connections for their clients and who only happen to be paid for their time.

Direct Experience with Individual

Historically, programs for the mentally handicapped focused on the teaching of skills in order to assist in the reintegration of these people from the institution back into the community. Indeed recent research has also emphasized social skill training for the mentally disabled (e.g., Foxx and Faw, 1992). Specialized teaching of social, functional, behavioral, and communication skills has sought to improve the presentation of individuals with mental disabilities in order to make their presence in the community more palatable to its more typical citizens. Yet in the present study it was found that across three individuals, all of whom had varying degrees of "socially inappropriate" behavior, the issue of acceptance seemed not to be predicated on their development of better adaptive skills. For

example, Dana was observed to impulsively interrupt some conversations, Dave's self injury reportedly often occurred in the community, and Dean engaged in various verbigerations and actions that might be deemed at worst offensive, and at best, odd. However, it was never observed nor ever considered by either staff or community members interviewed that any of these individuals should be removed from the community setting until they have learned to behave and interact as others do. These observations could speak to an overemphasis on the need to train people with mental retardation to be like people without mental retardation for the purpose of successful integration. Other factors that accounted for successful integration and acceptance of these three individuals, must have been at play in the present study. This has been already been implied by Butterworth and Strauch (1994) who found that perception of the social competence of disabled workers by nondisabled workers, could not predict the formation and maintenance of social relationships.

From the interview data it was clear that there seemed to be a path of desensitization that some community members went through in their connections with the participants with disabilities. There was an initial uncertainty, followed by the modeling of other community members and continued direct contact with the individual. Following this direct contact, an understanding of who the individual was as a person may have emerged, perhaps then leading to the acceptance of support and further interaction.

Observation of Dana during these interactions found a combination of social skill and social difficulty that seemed to be well tolerated by her community. Social competence of people with mental disabilities requires social cognition and social behavior, according to Greenspan and Granfield (1992). Dana's interactions were primarily found to be social in nature within a broad community setting. Therefore she may have fulfilled the criteria for social behavior and indeed have had the executive processes necessary to plan her interactions with others. Hence, she may be considered socially competent. However this criteria is likely not sufficient to judge the quality of the interaction because it only

presumes that if an interaction has occurred it must be psychologically satisfying and hence personally enriching. Past studies that have looked at the range and frequency of social contact for persons with mental disabilities have established patterns of interactions for people who live in a wide variety of settings and engage in a number of different segregated and integrated activities. However from a research perspective it is now necessary to judge not the propriety of these interactions, but the "goodness" of them in their ability to enhance the lives of people with mental disability. This may not be an issue of social competence or social integration at all. It may instead require a more in-depth understanding of each person's social requirements and who exactly can fulfill these requirements at home or in the community.

Dana was the most independent of the three observed and could function as a member of her community without her staff and hence the conditions under which she belonged to the town in which she lives, were determined to a large extent by her and the people of the town. This independence allowed her to utilize community businesses and initiate verbal contact on a consistent basis. The community responded in kind, though neighborhood interaction was observed to be negligible. However, both Sylvia and Sara were unsure as to their ability to accept Dave and Dean into their lives without facilitation of staff, and so Dave and Dean's belonging into their groups were more provisionary. Sara herself noted,

> "Sharon brings him by the store every now and then...but I guess we probably wouldn't really know (if we would see Dean again) until after Sharon has gone back to university or whatever and if he comes into the store with his mom or saw him on the street or something, whether he's going to know me or not."

It appears important that members of the community who are not certain how to interact with people with disabilities are able to model social behavior from other members of the community. Again this could not be done without direct involvement with the individual with the disability themselves, in naturally occurring situations. Modeling by

both staff and other community members allows people to engage or not engage the individual, try out ways of interacting, and receive support from either the staff or the other members of the community. If however, they are suddenly confronted with the individual and do not have the luxury of observing others' behavior toward that individual, their responses may vary. As Sandy stated "the people in the community don't have to look at us, they don't have to acknowledge that we're there, but people in the stores do", thus creating a forced interaction. The results of this type of "in your face" facilitation by Sandy has not resulted in a cry for the removal of Dave from the streets of his community. Instead it appears that Dave's presence has been more or less established, and the community has adapted as a whole and from interaction to interaction.

Though Sylvia, Dave's boss, seemed to downplay her own ability to be a professional in her field, it was clear through her interview that she recognized a key and commonsense component to being with people who have severe disabilities and helping them integrate. She stated:

> "The majority of the people I have in here doing the program or working...so called working for me, all have such disabilities like Dave being one that can't talk. So if they can't communicate, you have to watch to see how they're feeling ... or if they don't want to be there you can certainly tell."

Her comments regarding the behavior of the clients and relating that behavior to their desires reflect her understanding. It is necessary to know and understand individuals with disabilities in order to make their success a reality. This knowledge and understanding provides the foundation for planning a successful integration program that is built on individual strengths and needs and not simply on social skill training. In all three cases, in fact it has been the community that has adapted to the presence, behavior, and needs of Dana, Dave, and Dean. This has been done under their present conditions of staff and agency support as opposed to the three individuals being pre-trained to meet the supposed social and behavioral expectations of the

community. In these cases a step was skipped, calling into question the need for further socialization training in institutional and segregated settings as prerequisites for community involvement. Perhaps as found in the present study, communities have been underestimated in their abilities to welcome differences.

In summary, the data from the study found a process of desensitization that occurred only after repeated and consistent exposure to the clients and their staff. Through modeling, practiced interaction, and reinforcement from other community members, people who were not disabled could easily accept those with behaviors of concern, after they lost their initial fear or trepidation. This calls into question the need for continued social skill training for people with disabilities as a prerequisite to their acceptance in the community.

Individual's Personal Qualities

It appeared that the individuals' qualities, irrespective of their level or categorization of disability, helped determine how people reacted to them. Newton, Olson & Horner, (1995) found that staff members had taken on the role of friend after their business relationship with an individual with disabilities had ended. Reciprocity and the individual characteristics of the person with the disability were cited as some of the reasons for the maintenance of these relationships. Findings in the present study support these results and suggest that the disability and characteristics of the individual with the disability do not preclude those without disabilities from forming mutually beneficial relationships with them. It may be that staff are likely to form these relationships not because of any special training or knowledge but because they had the opportunity to get to know and understand the man or women, through working with them, and hence discover aspects of them that they found pleasurable. This then, may also be the fallacy of social skill training. Given the history of segregation of people with mental disabilities, it may have been erroneously assumed that individuals needed to be kept segregated until they had improved their adaptive living skills in order for them to be received well in the community. In her

interview, Sara pointed out that the exposure she and her teammates had to a child with a disability may have prepared them for Dean on their team.

It appears that evidence is mounting that acknowledges not only the community's ability to tolerate people with disabilities, but the community's acceptance and enjoyment of the people with disabilities for what they can contribute to their social group. A running theme of affection and positive regard was found from the interviews. In the present study, reciprocity between the participants was evident, whether it be on an emotional level as in the case of Sara and her team or a financial one as in the case of Sylvia. Here, the individuals with the disabilities had a function beyond that of client. They were able to give back monetarily to their community through access of community businesses and were able to contribute their own personal qualities to relationships. As Sara stated about Dean,

> "Well, he makes it more fun actually. He does. It's not as serious...we don't always have to be so serious and I think probably the same with everybody else. He keeps it light because ...he doesn't take it seriously and he always says something that makes us laugh. He does something or...he just kind of keeps us on our toes."

Sara may not have been able to specifically identify aspects of Dean that make him a wanted member of her group but it may be difficult for many people to clarify their affection for a friend beyond knowing that they like to have them around. Long standing friendships may only remain intact because the friends have always been proximally together. The friends themselves may not know exactly why their kinship has endured beyond the feeling that the relationship is comfortable, pleasurable, and wanted. Indeed the affinity of the team for each other was not observed to be based on common interests or intellectual levels, but on an enjoyment of being together, laughing and chatting about reasonably innocuous subjects and participating in an activity that all enjoyed. The baseball teams that were observed were heterogeneous in makeup. Some were married and had university degrees, and others were single and worked as mechanics. This social network was able to weave Dean in with ease perhaps because of its heterogeneity. The community

at large is also heterogeneous in the same ways. Perhaps that is why it is able to fit in individuals such as Dana who need some extra help in finding what she needs at the farmers' market, and Dave who takes extra rides in an amusement park just because the vendor knows that he likes to.

The concept of "community" is one that is important to the understanding of this study. For the purposes of this research, the term community has referred to the geographical boundaries of the towns where the study took place. A community is, however, more than simply boundaries and borders. A community is developed and maintained by the shared culture of its members. Whyte (1992) discussed the need for a healthy community that inspires loyalty but allows freedom of expression. He stated, "The free community will therefore not be afraid to handle conflict, and will see in the diversity of human view points and uniqueness of human personality an enrichment rather than a threat" (p.60).

Knowing, understanding and welcoming the uniqueness of these individuals appeared to factor into their ability to interact with their community members. Indeed the literature has found that reciprocity in relationships between people with and without disabilities accounted for at least part of the maintenance of these relationships. Specifically designing a program of inclusion that takes into account the individual's personal qualities, wishes, and ways of communicating may provide the framework for these bridges to be built. Eventually it is hoped that this positive regard outweighs negative perception.

There are several studies that have cited the influence and presence of family in the lives of people with mental disabilities. For example, Kennedy, Horner, and Newton (1989) found that families held the most stable and enduring of relationships in these people's lives and Krauss, Seltzer and Goodman (1992) found that this was especially true for persons who lived with their families. The family may have a dual function for people with mental disabilities. They may be able to form long standing relationships because of familial affection and love for the family member with the disability, and they may be able

to introduce their family member to a wide social circle that is not dependent on financial contingency. It may be beneficial then to reconceptualize the role of the community member as one that is closer to family than it is to staff. In doing so, perhaps, the benefits of the family role may be adapted by the community. It would also bypass concerns of the community that they could not take on a disabled friend because of their perceived lack of "training" or "patience." For example, Sylvia is apparently satisfied that her customers are accepting of Dave and the other volunteers in her diner: "So over the years the clients have gotten very....not involved... but they've gotten to know them so if Larry lets out roar, nobody takes offense". But there is not yet a shift to believing that she or her customers could move from tolerance to acceptance, to actually needing to have these people around.

There has been a suggestion to me that promoting relationships between the non-disabled and members of a community who are disabled, may lead to what has been apparently termed "the mascot phenomenon." This refers to the acceptance of people with disabilities by a the non-disabled because they are pleasant to have around; because they assuage any guilt about working toward the goals of inclusion but not actually practicing it; and because they function as a kind of a "badge" of inclusion honor. The data from this study may be similarly interpreted by some. For example, the ballteam's jovial interactions with Dean may appear condescending and trivial, therefore contributing to a "mascot" perception. However, I did not find the trend of interactions observed and reported, to be sympathetic in nature. But even if there was a component of charity, it may be something that is to be expected but not undesired. If compassion lends itself to the formation of relationships, this may be a necessary evil that people with disabilities might have to endure in order to become part of another's life. The problem is of course that while non-disabled people are able to have their requirements met in this type of relationship, the person with the disability is left to their partner's social mercy, cannot have any of their own intimacy needs met because of abuse issues, and may not be able to be a true equal or leader in the relationship. It becomes then a moral and ethical dilemma. In the push toward belonging,

inclusion, and equity, we overlook the psychological, social, and sexual needs of people with disabilities to have relationships with other people with disabilities. As more and more segregated programs for people with disabilities are being replaced with community-based activities, the logistical chances of a person with a mental disability actually meeting, not to mention falling love and building a life with another person becomes more improbable. It will be necessary to more closely examine the results of community options programs such as described in the present study in order to prevent the rhetoric of integration from sacrificing the important intimacy needs of people who have mental disabilities. As Goode (1990) noted, quality of life should be defined by the consumer rather than by the professional. How the social life of the person with the disability is evaluated ultimately depends on how well it satisfies them, and not their staff or agency.

Shafer, Rice, Metzler and Haring (1989) found in their study of co-workers that workers with severe and profound disabilities were perceived more favorably by their nondisabled co-workers than were individuals with mild or moderate disabilities. In the present study there did not appear to be an appreciable difference in the quality of community relationships had by Dana, Dean, and Dave. All, for the most part, were tolerated, even accepted and enjoyed by those observed and interviewed. What was missing of course was the extra component of a truly loved relationship partner, that component that is indeed found within families. The question of course is: can that component be trained, desensitized, and planned, and who should be the target of such a community relationship goal?

In summary, the data from the present study found that in the case of these three individuals with disabilities, their level of disability and behavior did not appear to impact the quality of relationships that they had with community members. There was an element of reciprocity both financial and personal that could not be identified, but seemed to be important for both partners. These relationships may have been marred by a component of

pity, but their value need not denigrate as a result. Relationships between people without disabilities may not always be equitable, but they will always be necessary.

Limitations of the Study

My study was limited in several ways. First, it is likely that other sampling strategies would yield different results and the small sample of those interviewed limited the generalizability of the findings to a population beyond those involved in the present research. My observations were conducted without the benefit of co-raters or videotape thus subjecting them to error. Third, replication of the findings would be difficult due to the uncontrolled conditions of the environment in which the observations took place. Finally, the themes generated are a product of my understanding of the content and context of the participant's words and may then be liable to my biases.

Implications for Further Research

1. Further research in this area should focus on the process of support-transfer from staff to community member. Experimental interventions that target increasing non-disabled community member supports of the disabled would assist in the planning of natural support circles for adults with mental disabilities in the community.

2. Measures of satisfaction of social support for people with mental disabilities should be developed and implemented. These measures should target perceptions of the person with the disability and would need to adapt to the communicative needs of the more moderately and severely disabled person.

3. Longitudinal research that compares the degree of acceptance between individuals who receive social skill training and those who don't would help to determine the efficacy and cost-benefit of social skill training for persons with mental disabilities.

4. Useful dependent variables to be used in experimental research include: the existence of staff support; the length of time the individual has been in a community; and the favorability of people with varying degrees of disability.

Recommendations For Service Agencies

1. From the data it is clear that staff who are assertive and have prior connections with their own home communities are able to facilitate relationships for their clients. Therefore it will be important for agencies to hire staff who are confident, outgoing, and familiar with their community.

2. Teaching social skills in a segregated setting in order to ready a person for integration and acceptance may not be necessary. Therefore in order to facilitate generalization and allow the community to get to know their citizen with a disability, social and adaptive skills should be taught in-vivo.

3. Slowly fade staff and transfer to natural supports systems only after the community member has had exposure to, understands, and likes your client. Data from the present study suggests that the acceptance of support may rely on modeling of the staff and other community members, an understanding of the client's needs, and a gradual affection for the client as a person.

4. My study suggests that service agencies consider the financial and tangible needs of the community when planning programs for their clients. By promoting reciprocity, it is possible that advantages to inclusion may be considered by the community that go beyond public pressure and philosophy.

Concluding Statement

Relationships between people with and without disabilities are in their infancy, and relationships between people with disabilities have lost research and ideological support. For some, the goals of normalization have surely been met. Slowly, institutions are releasing their residents to live, with support, in the communities from which they came. They are going home. People in the community can and will accept fellow citizens who were once systematically shunned and shut away. The degree of acceptance, however, may be contingent on a number of factors: whether that person has help, the quality and quantity of time they are able to spend with them, and whether they are tolerated,

understood and even liked by those around them. Criteria, perhaps, that we all must fulfill in order to fit in and belong in our world.

Those who care about people with disabilities often worry about them being hurt if they are given the chance to truly experience the range of human relationships. But people with disabilities deserve the right to experience all of human emotion, even if it includes heartbreak and disappointment. In fact, it is these shared emotional experiences that might finally bring people with and without disabilities together. When this occurs, the line of demarcation will truly be crossed.

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Appendix A-Consent Forms

My name is Marya Owen and I am a clinical psychologist and doctoral student at the University of Alberta. I am doing a study that looks at the social interactions between individuals with disabilities and their community.

Quality of life issues for people who have developmental disabilities recognize the need for social interaction within the natural community in order to facilitate social skill development and emotional well being. As more and more adults are moving from institutional or their parents' home to supported living in neighborhoods, there exists a need for contact with their neighbors and other community members.

The purpose of this study is to examine the patterns of existing social interaction between adults with developmental disabilities and their non-disabled community members. I would like to interview you for the purpose of gaining your perspective and opinion on how the community responds to your client. By gaining this information, I will be able to clarify and validate my own observations of the social interactions between persons with developmental disabilities and the community.

Your name, agency and town will not be divulged without your consent. You may choose not to answer any question and to terminate the interview at any time. When the interview has been transcribed, I will be happy to show it to you to make sure that your answers truly reflected your opinion at the time.

The results of this research will be of interest to guardians, administrators and staff of group homes and other facilities serving the needs of people who have developmental disabilities. The information gathered will likely provide insight into better ways of encouraging social contact between persons with and without disabilities in the community.

I have been adequately informed about the nature of the above study.

I _____(name of staff) consent to my participation in this study. I understand that I may withdraw from the study at any time.

_____

Signature of Staff Date

_____

Witness

My name is Marya Owen and I am a clinical psychologist and doctoral student at the University of Alberta. I am doing a study that looks at the social interactions between individuals with disabilities and their neighbors.

Quality of life issues for people who have developmental disabilities recognize the need for social interaction within the natural community in order to facilitate social skill development and emotional well being. As more and more adults are moving from institutional or their parents' home to supported living in neighborhoods, there exists a need for contact with their neighbors and other community members.

The purpose of this study is to examine the patterns of existing social interaction between adults with developmental disabilities and their non-disabled community members. I will need to gain access to information about your son/daughter/ward that will include their gender, age and nature of disability, some background information and general program information. Then I will observe your son/daughter/ward during their community options program and collect data regarding their interactions with their community members. **No names, names of agencies, names of staff or city or town locations will be divulged**. The results of this research will be of interest to guardians, administrators and staff of group homes and other facilities serving the needs of people who have developmental disabilities. The information gathered will likely provide insight into better ways of encouraging social contact between persons with and without disabilities in the community.

As well, participants with disabilities will be given $20.00 to thank them for their participation.

I have been adequately informed about the nature of the above study.

I _____(name of guardian) consent to the participation of _____in this study. I understand that he/she may withdraw from the study at any time.

_____

Signature of Guardian Date

_____Witness

Appendix B-Example of Data Collection Form

	Business	Neighborhood	Community	Client Initiate	Clerk	Co-worker	Staff	Social Verbal
Time								
10:15	1			1	1			
12:00		2						2

1=First Interaction

2=Second Interaction

APPENDIX C-Terms of Reference

Interaction-Reciprocal acknowledgment between the participant and at least one community member that may occur simultaneously or within a turntaking chain.

Nonverbal interaction-An interaction that involves mutual eye contact. May also include head nodding and smiling.

Social interaction-An interaction that involves a verbal initiation by either the participant or the community member. The initiation must be toward the communicative partner but the partner need not respond verbally. For example, if a participant bumps into a community member in the grocery store and the community member says "excuse me", even if the participant does not respond, the exchange would be considered a social interaction.

Functional Interaction-An interaction that occurs in order to further a necessary service. This may include giving information or completing a transaction.

Neighborhood-The neighborhood is considered to be within a 1 block radius of the participants home

Community-The community involves the area outside of the neighborhood and outside of places of business within a town or city.

Place of Business- Includes the area within a bank, restaurant, grocery store, mall and parking lot of the business.

Friend or acquaintance- An individual who is identified as such by the participant or the participants family or staff

Staff-A direct care worker currently working with the individual

Former or Other Staff- An individual who is familiar to the participant and who is currently employed or has been employed as a support staff.

Stranger- A community member who is not a friend, acquaintance or staff member.

Clerk-A community member who works for a place of business and is functioning in that role at the time of the interaction.
Co-worker- A person who works with the participant in their volunteer workplace or supported employment setting.

Initiator- The individual who first makes either nonverbal (directs eye contact) or verbal interaction is considered the initiator.

Appendix D-First Order Thematic Abstraction of Sue's Interview

Excerpts From Transcribed Interview	Paraphrased Meanings	Themes
1. I don't think it's hard for people that come from the agency to feel comfortable here because they know that this is a supporting place...the thing is, it's a lot different from here to a city or other places.	Living in a small town is better for newcomers because its more supportive.	Small town support
2. I think it's just the general feeling itself of a small town. People care more, they have more time to care, they take the time to care and I don't see that in the cities....you're even more rushed, it's more fast paced and that's probably just what it comes down to.	In a small town people slow down enough to care about others.	Small town support
3. I see it mostly with age and I think it's just because people know that they're not...they think they're not there but I think these people are all there more than we are...up here.	There is a general misconception about the cognitive abilities of the elderly.	Community misperception

4. They're (nonhandicapped seniors) not stupid people. They know what the heck they're doing and they....that's what I think people in the bigger centres don't see. They think they can see over them, but nobody sees over nobody. Everybody knows what they're playing with and I think it's just lack of respect and lack of communication and lack of support. I think so. And I think the reason it's so much stronger in our town is because the populations age is older and they know...and we have that respect here. We know what we're doing but in the older centres we're always mixed and so different in ages and this and that and everything. People just forget. They forget the perspectives.	Seniors in the small towns can relate and identify with the client and respect them anyway	Positive regard

5. I know we've had a few problems with kids in the neighborhood, but you know, I'm not the person to go out and speak for Dana. I'll tell Dana this is how it is and if you don't like it, this is what we can do, but you have to do it. Those kids were running and ringing the bell and knocking on the windows and all that craziness and I said well, there are ways you can handle this and the first thing we have to do is put up a no trespassing sign and if they still disobey it, then we'll go and talk to the police..I mean, you have to take your channels right, but don't...this is the way I would deal with it, (but it may not be) the way you deal with it.	I'm here to help support Dana and give her advice but not act for her	Staff mediation-support
6. We have a really good strong agency, that good people are in and Dana has to be brought up there too, but she is really coming around into her own.	Even though I work with Dana directly the agency is very important to her success as is her own personal work and development.	Staff mediation-agency support
7. But I told them at the agency if she doesn't want to move, I'm not going to make her move, but if she wants to go, she's ready.	I'm here to support her decision but it has to be her decision.	Staff mediation-support

8. She's got more confidence and a lot more....self esteem because I kind of know Dana's background and (former institution)...at any institution I don't think back in those days was a way to be brought up and that...those things really stick with these guys and some of them can be very damaged for life but I think the stronger ones that make it are like Dana and they come through it.	Despite the damage or the institution Dana's personal strength are able to function and be happy.	Staff mediation-understanding client
9. Just the same basic stuff that helps anybody...you get your support, you get the caring and the love and the right way to go and you go. But she's had a lot of good direction.	Dana's needs are no different than anyone else, she has thrived with support.	Staff mediation-support
10. She's friendly, she's open, she's honest, she's direct. She doesn't beat around the bush about anything. She'll tell you how it is and that's it.	Dana has qualities that help her in her relationships.	Positive regard
11. But I've always told her you know Dana, there's nothing wrong with making a scene when you meet your friends and everything and having fun, but you have to remember there's a good side, you have to remember what you're doing here and play nice.	Sometimes Dana is too attention seeking but I give her some advice of how to behave.	Staff mediation-assistance

12. Yes. And it's only when she's in a big group. But I think that comes from maybe that group thing at the old institution thing...how they're always in groups -the day rooms and all that and whoever made the most noise would get recognized and that's a hard thing to come over. But I don't see it as bad anymore, but it is still recognizable.	Her behavior is understandable given her institutional history, I have empathy for how hard that is to overcome and it is improving.	Staff mediation-understanding of client
13. Dana is a hard worker and she always stays on task, she's very determined and she always gets her job done and she's always cheerful. I think anybody recognizes that. That's just a strong value in a person and if you can do that, then they accept you.	Dana has personal attributes that others value.	Positive regard, Reciprocity
14. I believe in people and I believe to bring the best out in them and to make them live their lives as comfortably as they can.	All people can grow and develop and its my job to help them do that.	Staff mediation-support
15. Because Dana has an emotional problem...with my program, most of it is just the organizational thing like anything from grocery shopping to whatever. As long as she's organized and knows what she's doing, she could just walk in and do whatever she has to do and walk out. But if she doesn't have that, she's lost....It keeps her together. It keeps her mind together. Some people need that.	I know Dana needs help with certain things so that things go smoothly for her in the community.	Staff mediation-assistance

16. We do these programs and everything but I believe anybody needs moral support and the people that especially come out of institutions -they need to know this is normal living, this is how we do things and there's nothing wrong with getting angry or let loose once in awhile, but you do have to keep it together. But you have to know that we're here for you and that's all it is.	Clients must be supported in community and feel trust	Staff mediation-assistance

Appendix E-First Order Thematic Abstraction of Sara's Interview

Excerpts from Transcribed Interview	Paraphrased Meanings	Themes
1. Well I met him when he was working at ------at the--------News, when Mark was working with him - Sharon's brother. He was just delivering newspapers and it turns out my sister and brother-in-law own that newspaper. So I was in helping them one day and Dean was in. But I don't know if it was...I don't even think they really did an introduction, but that's the first time that I saw Dean.	I met Dean through my brother who was his staff.	Staff mediation-community connection
2. He's come in a few times to the store where I work with his mom and he always goes up and shakes hands and whenever he comes into the store, he's always wanted a stamp because he sees my stamps.	He accesses the community and initiates to me.	Client initiation
3. I guess I really didn't have a proper introduction to him until he was working with Sharon.	My friend who is his staff, introduced him to me.	Staff mediation-community connection
4. He always kind of catches Steve off guard. But Steve's getting more comfortable with him now.	There is initial uncertainty, but with time and exposure there is more comfort.	Initial uncertainty, Desensitization
5. She just introduces him. This is Dean and Dean this is whoever. And that's the way she always says it with the ball team too. And we always try to express him what our names are so that he'll remember what our names are.	There is an active plan on the part of his staff and the team to try and connect Dean to us and us to him.	Staff mediation-community connection

6. I think she just brought him. I'm sure she knew there wouldn't be a problem because we're all so good...we all went to school with kids who had disabilities too and I think that really helped us all.	There was an informal entrance to the team, but the staff had knowledge of the values of team.	Staff mediation-community connection, Desensitization
7. Just learning to accept people like that and they tried to integrate them as much as they could into our regular classes and stuff. Up until grade...probably grade eight or nine, we had a girl...I think Michelle had Cerebral Palsy...something like that. Anyways, she was wheelchair bound. She went to school in regular classes with us until grade four, then she had to be wheelchair bound and she still kept going to school with us until about grade eight...and that really helped all of us I think.	Exposure to disabled people in school helped us to understand and accept Dean.	Desensitization
8. Dean doesn't cause any problems. He keeps us entertained actually.	Dean isn't a burden, in fact we enjoy having him around.	Reciprocity, Positive regard
9. Well he always makes us laugh and I don't think we're really laughing at him, we're just...he's just so funny sometimes - just the things he says and his actions. The other night when he...I don't know what Sharon said to him, but he just turned and he looked at her and he ...It was so funny - just the way he looked at her.	Its hard to interpret our feeling for Dean but we enjoy having him there.	Reciprocity, Positive regard

10. I think everybody was a little bit leery at first, but then...well I knew to just treat him like a normal person because that's the way Sharon wanted him to be treated and I knew that's the way his mom wanted him treated because that was part of the reason why his mom encouraged Sharon to bring him out to ball so that he could be incorporated in with the rest of us. So when a couple of us start treating him just like a regular person, then the rest of...everybody else just jumps on the bandwagon.	Although we were initially nervous, we took our cues from the staff and then from each other and it was OK.	Initial Uncertainty, Staff mediation-community connection, Community modeling
11. I don't think there's anything really negative about Dean. He's loud sometimes, but you just learn to deal with it. It doesn't even phase us anymore.	Spending time with Dean helps us to get used to him.	Desensitization, positive regard
12. I just follow Sharon's lead. Like when he's loud and he's jumping up and down and stuff like that, she just usually comes in and says "Dean what are you so excited about?" and so that's pretty much what we...what are you doing Dean? and stuff like that and hopefully it will kind of snap him out of it. It usually does.	I trust the staff to show me how to behave with Dean.	Staff mediation-modeling

13. I think we really enjoy Dean. We were at a tournament August long weekend and Sharon...Dean was away at the lake and Sharon had other plans too so neither one of them could. (come). Halfway through the tournament we were sitting around the camp fire and I said I miss Dean! Because we're so used to having him around so he would have just had so much fun out there.	The longer Dean stays with us the more its seems he should be there, he belongs there.	Belongingness
14. Well, he makes it more fun actually. He does. It's not as serious...we don't always have to be so serious and I think probably the same with everybody else. He keeps it light because ...he doesn't take it seriously and he always says something that makes us laugh. He does something or...he just kind of keeps us on our toes.	Dean contributes a relaxed tone to the team.	Reciprocity, positive regard
15. I think actually the team with us all from high school, I think we are more comfortable with him. I'm not sure...Smith's they seem...that team seems to be opening up a little bit more to him now but, I'm not sure what....if Sharon caught them off guard or what. I don't know why there is a difference... Maybe it's because there are more people who play on the Smith's team and they're not always the same people at every game. It could be that reason too. So they just didn't have much of a chance to get to know him as the rest of us.	More time with Dean helps to get to know him and feel comfortable with him.	Desensitization

16. He is getting more and more comfortable...at the bar, when we take him to the lounge with us, he's getting more comfortable there and he's getting more comfortable at games. Like he'll go out onto the field in the middle of a game and we'll try to explain to him that it's not the time to go out onto the field!	Dean's comfort increases with repetition to us and the situation.	Belongingness
17. He tends to just keep to himself more with the Smith's team and I'm not sure why. I think maybe they just don't chat with him as much as the rest of us. I don't know. I'm not really sure.	We spend more time interactions with Dean so he's more interactive with us.	Reciprocity
18. We had to put him in a game...Thursday, we had to put him in the game because we only had six players and we needed seven before we could forfeit so we put Dean out in the field.	We need Dean sometimes and consider him a part of the team.	Reciprocity, Belongingness
19. I was worried about him because he kept having his back to the play, I thought he was going to get bonked on the head. But, I don't know...out in field....I don't know if he pays attention or not.	I feel that Dean is my responsibility as well and I care about what happens to him even if he has a staff.	Natural support
20. But he could probably back-catch just not out in field. And he can bat.	Dean has good skills that we could use.	Reciprocity, positive regard

21. Sometimes...like the other night, it was a couple of weeks ago, he ran out onto the field because there was a little boy and all he wanted to do was to shake his hand and I told Dean about that because he looked kind of leery at first and Dean does catch them off guard when he runs out. But after I told them he just wanted to shake his hand, then they seemed OK with it and Dean went back to the bench.	There was initial uncertainty, but I interpreted Dean's intent for them.	Initial uncertainty, Natural support
22. I've never been with him when he goes over to the bar, like the last few times we've been in there...he's more comfortable so if he wants something, he just says what he wants and then he jumps up and runs off to the bar and often Sharon is left running behind him! But I've never been over there....but I haven't seen the waitresses or the bar maids say anything to him.	The community seems to be accepting, Dean initiates and staff try to support.	Client initiation, Staff mediation-support, Belongingness
23. There's often times when we're leaving or something and he has to go around the entire bar and shake everybody's hand at every table and everybody...because he doesn't linger with them..he just wants to shake their hand and then he leaves. He might ask them to arm wrestle or something... but he never asks a guy to arm wrestle. It's always girls.	Client initiates interactions with the community, and it appears to be tolerated.	Client initiation, Belongingness

24. I was impressed the other...it was a long time ago, maybe even a month ago, I think it might have been the first game that you were at with the Smith's team. Stuart came late as usual, he came walking out onto the field and Dean was playing catch with Sharon and he saw Stuart and he ran right over to him. So I think he's getting to know Stuart and I hope that he's getting to know me. He doesn't call me by my name very often. He always calls me braces actually. He knows me by my braces. So I don't know if he calls me that with Sharon or not.	Dean is starting to make friends with the team, I like him and hope he likes me too.	Reciprocity
25. I don't know...out of the team, like the high school team, I'm probably the one that he knows the most because I see him away from the ball field. Sharon brings him by the store every now and then...but I guess we probably wouldn't really know that until after Sharon has gone back to university or whatever and if he comes into the store with his mom or saw him on the street or something whether he's going to know me or not.	I think I know Dean the best because I see him the most but when the staff leaves I don't know if our relationship will continue.	Staff mediation-community connection

26. I think they can be integrated into the community as much as...as much as they can, they should be. I think it's great with the (Parkview agency) and everything that they try to find their own homes to live in and try to find them jobs and stuff, things for them to do. And they learn things and they meet people. whenever somebody...it always seems like whenever somebody with a handicap comes in, I'm always the one that gets to work with them and it doesn't bother me at all actually. A few years ago it probably would have. But I think Sharon has really helped me open my eyes a little bit more. And all it takes is just being very patient and if you have to repeat yourself five times then that's fine. Just as long as they understand and I just keep remembering that.	My philosophy about people with disabilities is that they should be integrated. Knowing someone in the field and meeting these people has helped to arrive at this philosophy.	Staff mediation-modeling
27. Yeah, I think so...just people that are ignorant and don't know what they're doing. I think a lot of people don't know that...I think they just assume that all these people with disabilities that they see walking around town, that they live in a group home. I didn't realize that Steve lived on his own and he does quite well. And I think a lot of them do. That house...that group home isn't very big. It couldn't house all those people. Actually I'm not too sure who does live in there.	The community are negative because they don't know these people on an individual basis.	Community misperception

28. I think they just assume that they're all at the group home and they all just live there and don't do anything other than walk around town. But there's this (agency) that does good things. It sets up programs for them and stuff.	The community are negative because they don't know these people on an individual basis.	Community misperception

Appendix F-First Order Thematic Abstraction of Sandy's Interview

Excerpts From Transcribed Interview	Paraphrased Meanings	Themes
1..Dave is a tall, handsome..lovable, friendly, happy, he's a typical man that loves to ride in a car, loves to walk, doesn't like to shop and loves to eat. He's very friendly, he'll approach people on a friendly basis and give them big hugs.	Dave has many positive qualities that can be related to nonhandicapped people.	Client initiation, Positive regard
2. He has his preferences too. You don't see him approaching men, he likes to approach women - he's a real ladies man.	Dave chooses who he wants to initiate contact with just like other men its usually with women.	Client initiation
3. (I see myself as) a care giver, a supporter and someone who he can trust. He can come out into the community and experience new experiences knowing that I'll be there - if something goes wrong, I'll help him out and that's been proven. He'll do things hesitantly at first and then the next time you do it, he'll do it knowing that he can do it because I'm there to support him.	I provide support to Dave and facilitate his experiences.	Staff mediation-assistance

4. We were at the garden one day and we had to walk across some rocks and there was water flowing through the rocks and he just stood there looking and I encouraged him to go across the first rock and then he went across and as he went across the next rock he got more confident and then the next time we went across he just walked across knowing that it was o.k. Even on that bridge that we were on, he was very hesitant to go on that bridge, but then after he'd seen how much fun it was, you couldn't get him off of the bridge.	I help discover new things and repetition helps him learn and add to his repertoire of experiences.	Staff mediation-assistance
5. People look at Dave as if he's normal. Actually, we got called...we look like a married couple because he looks so normal and then people look at me when we take him to events and I'll say one adult and they'll look at and they'll look at me and then they'll either say are you his worker? or they'll just look at Dave and then they'll recognize that yes, he is handicapped. But they have to take a double look before they realize that he is handicapped. He's well dressed, he's always clean and his hair is...he has a nice short hair cut and he always smiles and he just doesn't look...as a first look he doesn't look handicapped, but the second look he does.	Because of how Dave looks and how we dress him, he integrates well into the community.	Staff mediation-community perception

6. When he reaches out to touch...and he does that, he reaches out to touch them or to hug them or whatever, they freeze at first thinking that there's this strange man reaching out to touch them so I'll look at them and I'll just reassure them that it's o.k. and they give that second look at and they say oh, that's no problem. They don't say well...they don't look at me as if get that man off me. This lady in the bathroom one time, I had him in the bathroom because I think it's easier for me to take him into the ladies washroom than for me to go into the men's washroom. This lady came in and was washing his hands and she looked at Dave like "what is he doing in here?" and I said to her...what I said it's easier for me to bring him into the ladies washroom than for me to go into the mans washroom and when she took her second look at Dave, she said "oh yes, I understand. No problem	They are scared initially, but then I interpret his actions for them and they are more accepting.	Initial uncertainty, Staff mediation-community education

7. We regularly go and buy chips at either the Mohawk store or there's a Lucky Dollar store and I like to have repetition so he can get to know the staff in the store and the staff get to know him and he knows where the chips are and he knows how to get there so I like to do that - take him there - and he has...he holds the money and they look at and they talk to him and they say it costs so much and they take his money and they hand him the bag so he's more accepted into the community and they look at Dave and they smile when he comes in because they know who is.	By exposing Dave to the same people and places they begin to accept him and recognize him.	Desensitization, Staff mediation-community connection
8. Because I told them this is Dave, he's coming in to buy chips and I sort of introduced him as. So he knows (the clerk).	I made it a point of introducing Dave to the clerk.	Staff mediation-community connection
9. Yeah, people recognize me with Dave. In fact, people I used to work with see me with Dave all the time and then one day I wasn't at work and someone else was working with him and they questioned me as to why I wasn't with Dave. Like where's your man?	The community expects Dave to be out and with me.	Belongingness

10. I don't think of it as well today I'm going to show the community what Dave can do. I don't do that. Today I pick up Dave and I say today Dave and I are going to go do this and we're going to enjoy that and I've never seen so many places since I've been working with Dave so it's like more of an adventure. I wake up in the morning as if it's an adventure. What are we going to do today...I think of it like that. How is Dave going to enjoy the day today? I don't think of how is the community going to accept Dave today? I just think how are we going to enjoy the day today or what are we going to do like when we go to the zoo, is he going to...how's he going to react to the animals? Is he going to want to pet them, is he going to want to eat a hotdog or is he going to want to get out of the van or that kind of a thing. I don't plan my day around the community.	I don't have an agenda to "integrate" I am more concerned with making sure his needs are met.	Staff mediation-understanding client needs

11. I think the biggest problem working at long term care was Dave's and I's attitudes. And I say and I because I had the same feeling like when I walked into the long term care, it was more of a solemn kind of atmosphere and we didn't feel comfortable there. We didn't. I could sense Dave's attitude towards it just changed from when we walked out of the van into the building and his attitude changed and I could just sense that and I think he could sense mine too because I had that same feeling and his abuse was up then and he'd have a couple of bad instances in the building that they had to remove him from but because of the program, we kept going and then when they did finally ask us to not come anymore, I noticed a great decrease in his behaviors.	I can tell what he wants and likes from his behavior.	Staff mediation-understanding client's needs

12. There was a couple of residents in there that knew Dave because he had been there for quite awhile and they knew so they were calling him by name, there were a couple of older ones that didn't like us in their rooms -they'd say, what are you doing in here? And then there were those who didn't care. But the nurses and what not, they accepted us. They knew what we were there for. So we were just sort of on our own. There was never really any stop and have a big conversation. They knew what we were there for and we just did our business.	We were accepted because we had a role and a job to do.	Belongingness, reciprocity
13. Well, the people in the community don't have to look at us, they don't have to acknowledge that we're there, but people in the stores do...	Dave can become invisible unless people are forced to acknowledge him.	Community intolerance
14. When they look at, they get that look like...what's wrong with him? And then I smile at them and then they smile back...	There is initial uncertainty until I intervene or until they understand our relationship.	Staff mediation-community connection, Initial uncertainty.

15. Once there was a little man sitting on a bench at the top of the escalators and the escalator going up stopped, so we had to walk up the escalator and ride down and continued to do this so I figured I'm going to out-do this man. I'm just going to....this is a marathon, I'm not going to give up first. So we did this about 15 times and this man kept watching us and he could sense...he knew that was handicapped and every time I come up, I was like a little bit more like..oh, can we stop now? He kept smiling at us and he was enjoying us. He thought this was kind of nifty that I was trying to keep up with this guy.	Even though was handicapped, he was enjoying us, taking pleasure from seeing us work together.	Reciprocity
16. I don't think I give them an opportunity to be negative. If they looked like something negative is going to come out - like that lady in the washroom - she could have said something negative like "what is he doing in here?" but before she had the opportunity, I said "he's in here because..." so I don't think there's been too many negative things.	I try to intervene for anyone can respond negatively.	Staff mediation-community education

17. We were walking down the mall and he didn't want to hang onto my arm, he wanted to go into one of the stores, but he won't go in alone, so I was walking down the mall waiting for him, I turned around and he walked up to this strange lady and gave her this big bear hug and I ran up to her and she looked...she looked like she was in fear and I said to her " is ok, he just wanted to give you a hug because he thinks you're so beautiful." and she looked at me and she smiled like she just melted and it was o.k. then, she was fine.	She was scared at first but I tried to put Dave's best foot forward and turn it into a positive experience.	Initial uncertainty, Staff mediation-community perception, Client initiation

18. Last week...the last incident that he had was in the Mohawk when he was getting impatient. He wanted his chips faster than what he was getting them and so he hit once and I held his hand down just so that he wouldn't hit with that hand again and I tried to calm him down by talking about the store and I wasn't getting upset at all and then he hit with the other hand so I held them both down and I took him into the van and I just calmly laid the seat back, put his helmet on and calmed down right away. So I've learned how to behave to his behaviors and without over-reacting - without yelling at him or telling him to stop because he can't do that. Then there was a young man who came out for me to sign the Dean and he could see what I was doing like he just kept...he stayed back, he didn't want to come and investigate what was happening, but he knew that was banging his head....he knew was getting his helmet on but he just stayed (back).	I feel confident about taking care of Dave when he's self abusive in the community.	Initial uncertainty

19. Like I said, he has his preferences. Some places he just will not go. We were supposed to go and check out Pizza Hut to see if they needed any volunteer work there so and I went into the building and we got in the door and he turned around and wanted out. So it was his decision -he did not want to go in there so we left to go to Boston Pizza...he loved to go to Boston Pizza so it wasn't like he didn't like to but some buildings scare him so he just doesn't go in there.	I respect Dave's decision even if it mean losing a place for him to access.	Staff mediation-understanding client's needs.
20. There was two people behind and I looked at the expression on their face and they looked like...what is he doing that for? That kind of thing. They looked puzzled at him and I just...like I said I just calmly just walked him out of the store without panicking or getting upset. So they calmed too, you could see that their reaction was oh she knows what she's doing, she knows how to handle it.	Although the customers were initially apprehensive they were ok with the staff there.	Staff mediation-modeling

21. Actually one of the store clerks daughters...or one of the store clerks is the daughter to a worker so I think she knows that Dave has behaviors, so she just went on about her business. She didn't...like it didn't stop her from doing what they were doing. They just continued to work and help the customers out. They're very good in there - at the Mohawk.	Dave is well known to the people in the store and that exposure helps them to understand him.	Desensitization
22. I took him back in there again and it was just that he was not happy that day..it wasn't like anything...it wasn't about the store or anything about...he just wanted his chips faster than what they were doing.	Dave's behavior doesn't preclude him from accessing the community, unless it tells me he doesn't like someplace.	Staff mediation-understanding-client's needs

23. I took him to the (complex) down the street and I thought well, I'll take him out of the community so no one has to see what I'm doing in the car, and I thought I was doing the right thing and I had his helmet on him and this RCMP officer came up because he had seen my car sitting in the parking lot and he said...I had my dog with me too and he says "Are you taking your dog for a walk?" I said "I'll be right with you in a minute officer, I'll tell you what I'm doing in a second." So I got out of my car and I went over and I opened my car door, rolled down my window so couldn't put his head through it and laid the seat back so he could relax, calm down and I went over to his car and I told him what I was doing. And he says o.k, no problem. So he had seen what I was doing.	There is initial uncertainty until I intervene or until they understand our relationship.	Staff mediation-community education
24. People would come to you and open the door for you..if you have a wheelchair they'll open a door for you...they would just sit there and look at you come in like they didn't like you there so why would they open the door for you?	I could tell from the people's behavior and lack of assistance that they didn't like handicapped people.	Community intolerance
25. Yeah because they're reluctant to say hi because they don't know which one of us is handicapped. That's what I think.	People have a hard time understanding the situation and relationship initially.	Initial uncertainty

26. We went to the parade there and let's see....we had to walk to parade route because he wouldn't stand and everybody just...like excuse us and they look at us and they get right out of our way. One time I asked if I could please get in line at the grocery store, could I please get in line ahead of you because I have and he's impatient, they just move right out of your way.	People in the community are generally very cooperative and positive and helpful with Dave and I.	Staff mediation-community education, Community tolerance
27. And there was a guy working there and I said that Dave would love to get on those horses, he would...he really did want to get on it and I said without having to pay could I maybe see if he'd get on and if he gets on could we go for just a little ride? And he said...oh..he'd have to ask his...but he did agree to it. We got on there and he just loved it. Went around and around. And then of course at the museum, she was fantastic. When she saw Dave I said this is Dave, she looked at him and I said he'd love to get on your ride and she let him on there and every time I said he'd like to get on again, she just said ok, no problem. There was no problem. That was great.	When I advocate for people have been very willing to accept him and help him.	Staff mediation-community connection, Community tolerance

28. They go through me. They see me, the clerks see me, they say hi to me and they see, they know can't say hi or whatever, but...so when they're saying hi to me, I think they're saying hi to both of us. That's how they.....In Walmart we don't really do any shopping other than chips. He takes the bag, walks it to the counter, and I give him the money that way they have to interact with him _ taking his money.	The clerks are more comfortable talking to me but I try to force them to interact directly with Dave so that they see him too.	Initial uncertainty, Staff mediation-community connection
29. They react to him just like he's a child. Thank you..ha ha..they say thank you to him and then they hand me the change.	They do not see Dave as a man, and try to interact with me instead.	Community misperception
30. I try to take him to the mall in the community without having to integrate again in the summer time, but we're trying to stay away from there because then you don't want to be known as "oh, here they come again.	Even though the mall is a good venue for Dave, I don't want him to be perceived as a freeloader or where out his welcome.	Staff mediation-community perception

31. I don't want them to think of Dave as that "retarded man" coming in and making a mess of the tables and I don't want them to think of him like that. When we leave a table, we leave it clean. We pick up our tray...like he's dropped chips on the floor, I'll pick them up because I don't think it's...it's not necessary for them to have to get up there and pick them up...but I'll make sure the table is clean when we leave so that there's no...oh there's that man coming back again leaving a mess.	Perception of Dave should be positive and staff should mediate that.	Staff mediation-community perception
32. I want them to know Dave that it's o.k. that he is controllable and that he's not going to hurt himself or anybody else and that I'm not going to panic....	I want to educate the community about Dave.	Staff mediation-community education

33. There was a chair, he sat down, I started folding towels in preparation for hanging them up and he started hitting and I grabbed his helmet and there was a nurse who had seen this and she said "do you need any help because I used to be a PRN" I said I can handle it and then she could see that...he was on the floor now and trying to put his helmet on and he's on the floor and she come over and she was going to assist me and he was laying...the helmet was on and he was banging his head on the floor and I put....she put her hand inside the helmet _ the face _ and picked him up by the head and was holding him like that so he wouldn't bang on the floor. But she was holding him like he was an animal and I was just...maybe I was too passive, I should have said excuse me, let him go like Julie would have but...I didn't. I just thought, she used to be a PRN, she knows what she's doing kind of thing. They wanted to put him on a stretcher and tie him down and get him out of there so she made a big production of it all and there was another worker there who came and he brought the gurney and I said there's no way you're going to put him on there. I said he could walk out of here, just let him calm down first. No, they wanted him out of there. So they got the gerry chair and they put him in that and they put the tray across from him and I got him out of there as fast as I could. I didn't want people to stare at him. I got him out the door, he got up and walked to the car.	Other professionals treat without knowing who he is or understanding him.	Community misperception

Appendix G-First Order Thematic Abstraction of Sylvia's Interview

Excerpts from Transcribed Interview	Paraphrased Meanings	Themes
1. Sandy brings him over the serviettes and she helps him fold them and put them in the container and then he gets a treat - his chips.	Sandy gets him started, helps him with job, and provides reinforcement.	Staff mediation-assistance
2. The majority of the people I have in here doing the program or working...so called working for me, all have such disabilities like Dave being one that can't talk. So if they can't communicate, you have to watch to see how they're feeling ... or if they don't want to be there you can certainly tell.	It is necessary to know the non-verbal client, to be able to predict behavior and serve needs.	Knowledge of individual's needs
3. And if he keeps the same worker, he's fine....that seems to be a problem too..	Staff consistency is difficult, and may lead to problematic behavior.	Staff mediation-consistency
4. If he has the same worker but as soon as workers change, then there's behaviors that..	Staff consistency is difficult-may lead to problematic behavior.	Staff mediation-consistency
5. Initially we took them when there was no customers in here because we were new to the restaurant and we didn't know how they'd react.	The risk to the restaurant was unknown initially initial concern or worry due to lack of experience with situation.	Initial uncertainty
6. And as the weeks and months went by we kind of went well, customers might as well just get used to them because we're wheelchair accessible and we're accessible to them regardless.	Our philosophy changed, the customer's opinion did not matter -we were set up for them so we will welcome them.	Desensitization

7. So over the years the clients have gotten very....not involved - the customers I should say - not involved but they've gotten to know them so if Jay lets out a roar, nobody takes offense.	The customers have gradually become used to the clients.	Desensitization
8. There are new ones at times but they see the reaction of the other customers and nobody seems to be excited so they don't get either.	The customer's take the lead of the other customer's in reacting to the clients.	Community modeling
9. There's a few of the clients that are fairly outgoing and the customers respond. They'll shake hands or they'll say hello	The client's initiate social contact and the customer's respond positively.	Client initiation
10. the workers keep them fairly separated which I do prefer because I do know the history of some of them and what they can exactly do if they feel threatened or afraid or startled	The workers direct the amount of social interaction between the client's and staff in order to avoid problems or danger to customer.	Staff mediation-safety
11. I've only ever had one negative comment and it was how can you stand them in here? And I'm going probably better than you.	The customer's have virtually all responded positively to the clients.	Belongingness
12. I think I have an advantage over probably 95% of the places in town because I've been doing it for so long, I have the same basic customers and the workers have gotten to know so well that I don't even have to come and say "could you please keep them quiet" or "they're making too much noise." They just automatically do it here as if they do it any place else.	My situation works well because the customers, clients and staff are all used to the routine.	Belongingness

13. It's the whole thing goes back to if the staff is comfortable here, the client will be- the customers aren't staring up or we're making them feel different, I don't see any of the clients acting out like they could somewhere else or have. Some will come here when they won't go other places only because no one bothers them. They have to do what they're told, they don't get away with anything but they don't feel intimidated or different.	This is a haven for the client's and their staff where they know they will be welcome.	Belongingness
14. They're not stared at or people don't move away from them like they don't want to be within a table of them.	The customers are not afraid or repelled by the clients.	Belongingness

15. I think it's more important that the people working with them has a place to go where they can feel comfortable. For every client there's a worker....that's a big work force here in town. Looking from a business perspective too, it's a big work force so if they like it here, chances are they'll come back with their families or just say it's a good place to go. I look out for myself too! Well so if I lose two customers in a year because they have something against being in the same place with handicapped, well I'm sorry. I get the other side of it. But having the workers coming in here and the clients working....there's a lot of programs going in here which makes my life a lot easier. So I don't mind working a monthly bingo or something where they'll get the benefit of the money.	By providing this venue for their clients I am able to attract more business for myself.	Staff mediation-reciprocity
16. There's disabilities and disabilities. The ones that I have here are severely disabled. They could no more...maybe do something for a very short period of time on their own or you show them, but the majority can't so you take a lot of hands on, one-on-one helping.	I understand the level of support these client need and its very intense.	Staff support - assistance
17. So that really wouldn't really be fair for me to say to anybody that they should take somebody.	Although this arrangement works for me, I would not push others to do it.	Knowledge of individual's needs

18. Some days the same ones don't come and there's new ones that you have to show what to do, but they seem amongst all of them to organize themselves in the morning. I don't have to be concerned that something is not going to be done.	The staff are fairly autonomous and don't need much of my time due to the length of time we have been doing this.	Staff mediation-reciprocity
19. I think because they want to do it. Nobody feels sorry for me! I don't know... I haven't a clue. I think they just like coming here.	The arrangement is pleasant for everyone the staff and clients enjoy coming here and I enjoy having them.	Belongingness
20. I could leave...well actually I have on different occasions if there's errands that I have to run, I'll leave them here, if customers come...they can look after them.	I know I can count on and trust the staff.	Staff mediation - reciprocity
21. Even in a bigger center, a block is still a block no matter where you go. So you have your....if it was a restaurant like this, if it was a family restaurant, you'd just have the same people coming. So if you had a program - say the handicapped or the physically disabled or mentally disabled coming in, you'd probably have the same ones coming with the same workers .	It is the type of business you have and the length of time spent with the staff and client that is important not the size of the town.	Desensitization
22. It would be really hard for me to have a problem with a client because their workers are actually responsible for them so it would be the worker I'd have the problem with.	The client's are not responsible for their actions, the staff are.	Staff mediation-responsibility

23. Another worker would probably fill them in or tell them something is being misappropriately done or you shouldn't be doing that or maybe you should keep a better eye on so and so, they're not to go through the kitchen. Things like this have happened or they'll go charging down the hall and somebody could be visiting and never notice. .	The staff are responsible to each other for the safety and well being of their clients.	Staff mediation - modeling
24. I think it's pretty well self-checked themselves. I think maybe a lot of it is they (the staff) don't want to lose the place as a place to be. At least I hope it is.	The staff monitor each other in order to maintain this site.	Staff mediation- reciprocity